

10 - 22 MARCH 2024



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



Acknowledgements

CLAN (Caring & Living As Neighbours) 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, CLAN acknowledges the Wallumedegal Peoples of the Eora Nation, on whose land CLAN is headquartered. CLAN pays its respects to Elders past and present and extends that respect to all First Nations peoples around the world.

CLAN thanks the many individuals involved in organising and presenting at this event, with especial thanks to our Australian New Colombo Plan Scholars and CLAN Community Development Officers, Mabel Cudmore and Elizabeth Page who coordinated and chaired this event.

Further, CLAN thanks the many organisations who have generously contributed to the @MATES4Kids (Maximising Access to Essential Medicines for Kids) movement and helped make this event a success, including:

- CAH International
- Colonial War Memorial Hospital, Fiji
- Child and Youth Care Zimbabwe
- Intersex Philippines
- University of Colombo, Sri Lanka
- Diponegoro University, Indonesia
- Indonesian Paediatric Society
- SiEndo Foundation
- New Colombo Plan

The New Colombo Plan is a signature initiative of the Australian Government that aims to lift knowledge of the Indo-Pacific in Australia by supporting Australian undergraduates in studying, learning languages, and undertaking internships in the region. CLAN and our many partners across the Asia Pacific region (notably Indonesia, the Philippines and Fiji) have hosted more than ten NCP Scholars since 2017.



Fig 1: Australian New Colombo Plan Logo

This event was dedicated to the mother of Ms Trudy Nyakambangwe, who sadly passed away just days before the event. As a UN Women's event, CLAN felt it was appropriate to acknowledge the life of such a remarkable woman. A moment of silence for Trudy's mother was held at the conclusion of Andrew Twineamatsiko's opening presentation.

Table of Contents

Acknowledgements.....	1
Table of Contents.....	2
List of Abbreviations	3
Executive Summary.	4
Key recommendations.	5
Advocating at UN #CSW68.....	6
CLAN’s Written Statement:	7
The @MATES4Kids virtual side-event at #CSW68.....	8
Agenda.....	9
Welcome and Introduction.....	10
Introduction to CLAN.....	11
Introducing the @MATES4Kids Movement.....	12
The importance of hearing one another’s stories.....	14
Celebrating CAH in Fiji.....	15
Building the CAH Community in Zimbabwe.....	16
Living with CAH in the Philippines.....	18
Research and Action for CAH in Sri Lanka.....	20
An update on CAH in Indonesia.....	24
The Colombian CAH Community Unites for Change.....	27
Living with CAH in Colombia.....	30
Concluding comments and reflections.....	31
In-person participation at #CSW68 by CLAN’s UN Youth Representative.....	32
Appendix 1 – Full text - CLAN’s Written Statement for UN CSW68.....	33
Appendix 2 – Guide to Joining the @Mates4Kids Community of Practice on the WHO Knowledge Action Portal.....	37



List of Abbreviations

Abbreviation	Full text
CAH.....	Congenital Adrenal Hyperplasia
CLAN.....	Caring & Living as Neighbours
CSW68.....	68th Session of the United Nations' Commission on the Status of Women
NGO CSW68.....	Non-Governmental Organization Commission on the Status of Women Forum
HIC.....	High Income Country
MATES4Kids.....	Maximising Access To Essential Supplies for Children
LMIC.....	Low-Middle Income Country
NCD.....	Non-Communicable Disease
NGO.....	Non-Governmental Organisation
NCP.....	New Colombo Plan
SDG.....	Sustainable Development Goal
NBS.....	Newborn Screening
UN.....	United Nations



Executive Summary

CLAN (Caring & Living as Neighbours) was proud to engage in events relating to the Non-Government Organisation Forum at the 68th Commission of the Status of Women in 2024.

CLAN's overarching goal in engaging in #CSW68 was to enhance the work of the @MATES4Kids (Maximising Access to Essential Supplies for Kids) movement; support initiatives to reduce the preventable mortality associated with congenital adrenal hyperplasia (CAH) by 30% by 2030; and meaningfully contribute to collective efforts to achieve the Sustainable Development Goals by 2030.

The CSW68 Priority Theme was:

“Accelerating the achievement of gender equality and the empowerment of all women and girls by addressing poverty and strengthening institutions and financing with a gender perspective”

This event was a unique opportunity to privilege the voices, stories and perspectives of girl babies, women and those born biologically female with CAH.

Key Recommendations

Speakers from around the world highlighted the importance of maintaining momentum on @MATES4Kids' three key objectives to reduce mortality:

1. Improving access to essential medicines and equipment
2. Scaling newborn screening; and
3. Strengthening CAH communities

These same activities offer the best hope for redressing the gender inequalities associated with CAH in resource poor settings.

This event offered a unique platform for the voices of all people born biologically female with CAH to share their stories and perspectives... we hope this is just the start...

The voices and needs of people living with CAH and other non-communicable diseases (NCDs) must guide all efforts to drive change, and the five pillars of CLAN represent a robust starting point ensuring multisectoral collaborative action addresses community priorities.

Advocating at UN #CSW68

CLAN supported @MATES4Kids participation in CSW68 through three key activities:

1. Submission of a written statement
2. Hosting a virtual UN NGO CSW68 side-event for the @MATES4Kids Network
3. Participation in face-to-face events at CSW68 by our UN Youth Representative, Katie Blomkvist, and

A video recording of the event is available on CLAN's YouTube account [here](#).



Figure 2: Screenshot from United Nations NGO CSW68 Forum Side Event hosted by CLAN in partnership with @MATES4Kids & Lehigh University on 13th March 2024.

CLAN’s Written Statement:

CLAN was proud to facilitate submission of a published written statement to ECOSOC that speaks to essential role NBS must play in providing early diagnosis and treatment for women and girls living with non-communicable diseases, and thereby achieving the SDGs by 2030. The statement is available via the United Nations [online](#), and provided in entirety in Appendix 1 of this report.

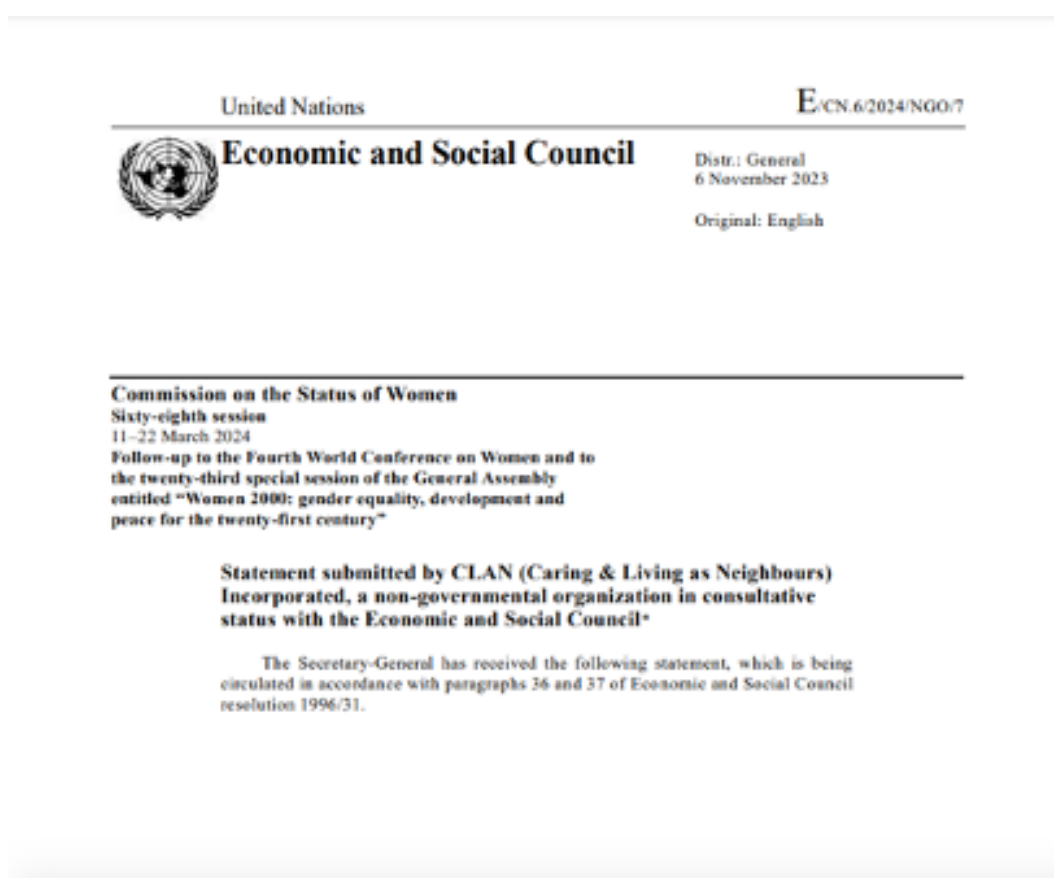
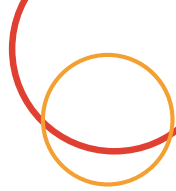


Fig 3: CLAN Official Written Statement Partial Screenshot



The @MATES4Kids virtual side-event at #CSW68

CLAN was proud to host a virtual side event at the 68th Session of the United Nations' Commission on the Status of Women (CSW68) on the 13th March 2024, in partnership with @MATES4Kids, Lehigh University, and global changemakers to discuss the role of improving access to essential medicines and equipment; strengthening CAH communities; and scaling universal newborn screening programs in promoting gender equality and empowerment for CAH communities.

The side event was titled “Accelerating gender equality and empowerment for the international CAH Community” and brought together experts from around the world to highlight the importance of these initiative to achieving the Sustainable Developments Goals (SDGs) and reducing gender inequalities affecting all children and adults who are biologically female and living with CAH in resource poor settings.

Speakers from Australia, Zimbabwe, Fiji, The Philippines, Sri Lanka, Indonesia, and Colombia participated, representing a broad range of NGOs, organisations, and CAH communities participating in the @MATES4Kids network – all committed to achieving the bold and collective goal of reducing the preventable mortality associated with CAH by 30% by 2030.

Agenda

Subject	Content	Speaker / Representative
Introduction	<ul style="list-style-type: none"> • Summary of CSW68 • Introduction to NCP partnership • Introduction to Congenital Adrenal Hyperplasia 	Mabel Cudmore
Introduction to CLAN	<ul style="list-style-type: none"> • Introduction to CLAN & Framework for Action • Introduction to CLAN Africa 	Andrew Twineamatsiko
@MATES4Kids Introduction	<ul style="list-style-type: none"> • Introduction to @MATES4Kids • Vision to achieve 30x30 	Kate Armstrong
Living with CAH in Fiji	<ul style="list-style-type: none"> • World Children's Day and International Day of People with Disabilities event 	Ili Vereti
Living with CAH in Zimbabwe	<ul style="list-style-type: none"> • Achievements of the CAH community in Zimbabwe 	Trudy Nyakambangwe
Living with CAH in The Philippines	<ul style="list-style-type: none"> • Progress and challenges for the intersex community living with CAH in the Philippines 	Jeff Cagandahan
Optimising diagnosis treatment and support for CAH Communities in Sri Lanka	<ul style="list-style-type: none"> • CAH diagnosis in Sri Lanka • Gender-based issues for girls with CAH • Treatment and management of CAH 	Sumudu Seneviratne
Optimising diagnosis treatment and support for CAH Communities in Indonesia	<ul style="list-style-type: none"> • Progress of CAH Newborn Screening program in Indonesia • Access to CAH medicines in Indonesia 	Agustini Utari
Colombian CAH Community unites for change	<ul style="list-style-type: none"> • 1st Colombian CAH Club Meeting • Story from a CAH community representative 	Paola Duran Anghela Caestro
Closing Remarks	<ul style="list-style-type: none"> • Closing remarks and recommendations for next steps 	Kate Armstrong

Welcome and Introduction

Mabel Cudmore

Australian New Colombo Plan Scholar
CLAN Community Development Officer



Connecting the CSW68 theme to the Lived Experience of CAH Patients Assigned Female at Birth

At the CLAN and @MATES4Kids side event at the 68th Commission on the Status of Women, we presented our session titled “Accelerating gender equality and empowerment for the international CAH Community.”

The focus of the session was on empowering the voices of those assigned female at birth who are living with CAH as well as highlighting the importance of newborn screening as a tool to promote early and equitable access to diagnostic and therapeutic options for children living with NCDs. In addition to NBS, the session highlighted the essential role of access to medicines and strengthening communities in reducing the preventable mortality associated with CAH and supporting efforts to achieve the Sustainable Developments Goals (SDGs) by 2030.

Congenital Adrenal Hyperplasia

CAH is an inherited condition affecting the production of two hormones by the adrenal glands – cortisol and aldosterone. Fortunately, CAH can be treated with two essential medicines: hydrocortisone and fludrocortisone. When these medicines are used, children with CAH should expect to live long, healthy and happy lives. Unfortunately, children and families living with CAH in resource-poor settings often are not able to affordably access the care they need to survive and thrive.

This UN Women event was a chance to focus on the experiences of girls, women and all those born biologically female and live with CAH deserves special attention. Many times these CAH Community members experience unique and life-altering experiences with CAH. Many families and people living with CAH in resource poor settings report experiences of extreme isolation and social stigma, particularly when limited access to affordable medicine and quality healthcare impacts on a child’s growth and development in ways that don’t conform to what is culturally expected of their gender.



Introduction to CLAN

Dr Andrew Twineamatsiko

Community Development Officer, CLAN Child Health Africa
Medical Doctor & Public Health Specialist, Uganda



About CLAN

Andrew provided an introduction to CLAN (Caring & Living As Neighbours) as an Australian based organisation (now incorporated as CLAN Child Health Africa in Uganda), that aims to maximise quality of life for children and their families living with chronic health conditions in resource-poor settings across the world.

CLAN’s Strategic Framework for Action takes a rights-based, community development approach, with all collaborative action focused on five pillars, as shown in the figure below.



Fig 4: CLAN’s Strategic Framework

CLAN Child Health Africa

CLAN Child Health Africa is an affiliate organisation of CLAN which aimed to advance CLAN’s mission in the Africa region by utilising this same Strategic Framework for Action. Through community owned, controlled, and led support group organisations, CLAN Child Health Africa has supported projects in Uganda, Burundi, and Zimbabwe, with hopes to reach more countries and communities in the future.

- Uganda: Nodding Syndrome and Epilepsy Communities
- Burundi: Type-1 Diabetes Community
- Zimbabwe: CAH Community

Introducing the @MATES4Kids Movement

Dr. Kate Armstrong
President & Founder, CLAN (Caring & Living As Neighbours)
Co-Chair @MATES4Kids



@MATES4Kids (Maximising Access To Essential Supplies) is a global movement of individuals and organisations committed to reducing the preventable mortality associated with CAH by 30% by 2030.

Achieving 30 x 30

@MATES4Kids is committed to ongoing efforts to reduce the preventable mortality associated with CAH by 30% by 2030 through collaborative, international action that focuses on three key objectives:

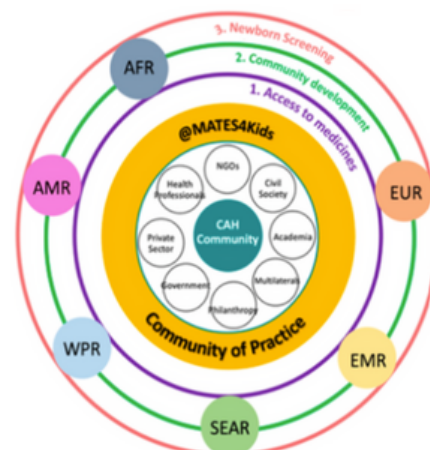
1. Improving access to essential medicines & equipment: Kate acknowledged the work of teams in Colombia, Zimbabwe and other regions of the world to improve access to CAH medicines across the globe.



2. Strengthening CAH community development: Recently there have been a number of CAH Community events around the world, including an inaugural CAH club meeting in Colombia; celebrations in Fiji, and a recent meeting of CAHSAPI in the Philippines. Of particular note, different communities around the world are now reaching out to one another to share messages of encouragement and support. An example was shared of a message sent by KAHAKI, the CAH family support group in Indonesia, to Colombia.

3. Scaling newborn screening (NBS)

Connecting & Celebrating Champions is a key strategy the @MATES4Kids Movement uses to drive collective action to achieve our shared bold goal. Quarterly meetings unite @MATES4Kids members, with representatives from each of the six WHO Regions participating and sharing their successes and achievements towards each of the three objectives.



@MATES4Kids is grateful to WHO for allowing us to use the Knowledge Action Portal as a platform for sharing key information, tools and resources. You can find a guide to join the KAP in the appendix.

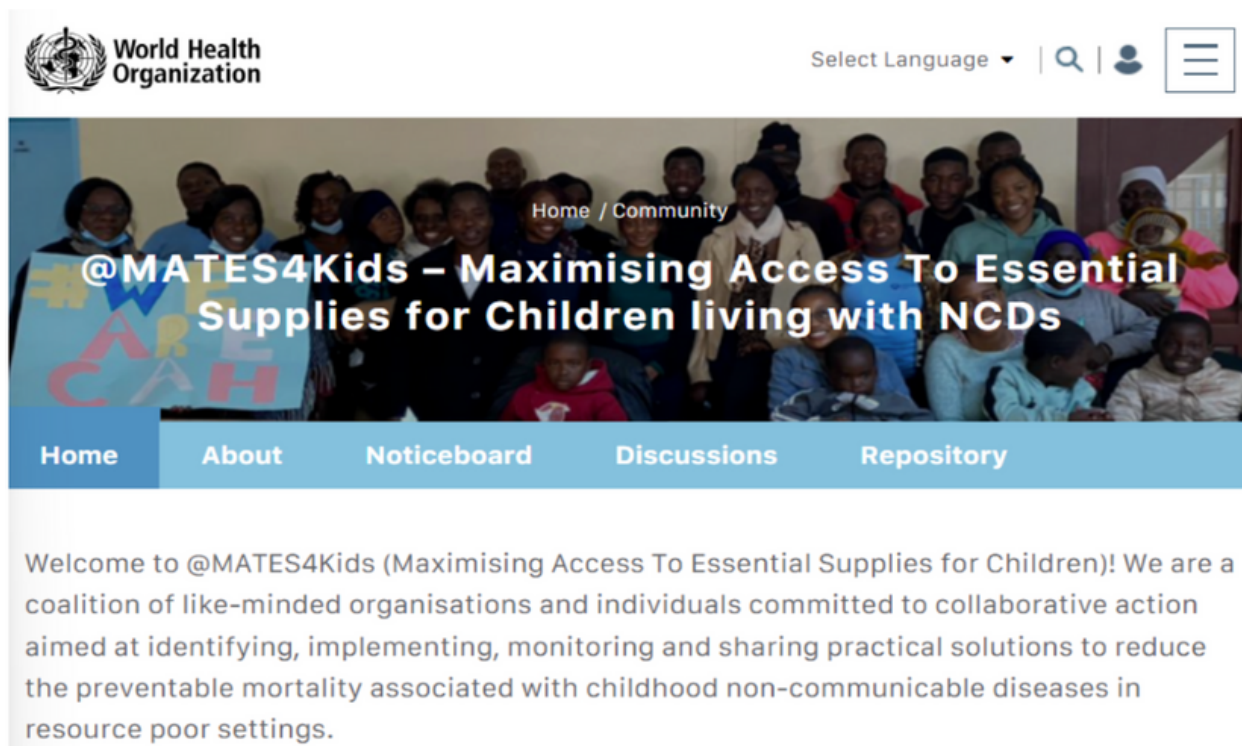


Figure 4: WHO @MATES4Kids Knowledge Action Portal

The importance of hearing one another's stories

Lesley Holroyd

CAH International
CARES Foundation



This event acknowledged the very different experiences of people living with CAH in high and low-income countries. As part of celebrating CAH champions, CLAN was delighted to share information and links to the story of an amazing woman living with CAH in the USA. CAH community representative and champion Lesley Holroyd was scheduled to speak at this event, but sadly fell ill on the day. We are delighted Lesley has since fully recovered, and generously given permission for us to share her story as part of this report...

Lesley's Bio:

My name is Lesley Holroyd. I was born in 1957 in a small town in the south of England. I was born with salt wasting Congenital Adrenal Hyperplasia (SWCAH). I was the first family member to have CAH. I have 4 brothers and one sister, my youngest brother lives with classic CAH too. My siblings still live in England. I moved to the USA in 1991 with my husband. My step- daughter followed us several years later. I have 4 grand- children and 5 great grandchildren.

I am a registered nurse and recently retired after a 40 plus career. I have never let my CAH define me or stop me completing my dreams and goals in life. My husband passed away in November of 2020 after 40 wonderful years, .I now dedicate my time being a patient advocate for the CAH community. I volunteer with CARES Foundation and CAH International.

I like to share my CAH story with others to raise awareness and show others that they do not feel alone and that we are all on this journey together. I live my best CAH life one day at a time.

You can hear more about Lesley's story in her wonderful podcasts:

- Pt. 1: <https://cahpulse.podbean.com/e/lesley-part-1-feeling-lucky/>
- Pt. 2: <https://cahpulse.podbean.com/e/lesley-part-2-i-don-t-want-others-to-feel-like-i-did/>

Celebrating CAH in Fiji

Dr. Ilisapeci Vereti Tuibeqa

Head of Paediatrics Department – Colonial War Memorial Hospital, Fiji



Celebration of World Children’s Day and International Day of People with Disabilities event in Suva on 24th November 2023

Dr Ilisapeci’s presentation provided updates on a CAH Community event in 2023 that coincided with World Children’s Day and the International Day of People living with Disabilities at the Colonial War Memorial Hospital in Suva, Fiji. The purpose of the event was to celebrate and acknowledge the CAH community in Fiji, whilst also connecting families in with a broad range of stakeholders and organisations doing great work to promote child health.

Nine CAH families in Fiji were in attendance on the day, as was the Australian High Commission First Secretary of Health, Ms Fleur Calcutt and various other important stakeholders. The event was also fortunate to have media support through the presence of national media outlet Fiji Sun. Health professionals provided updates, and CWMH paediatrician Dr Emily Vadiga delivered an educational speech for CAH families and guests.

Parent Testimony: Mr Isimeli Cacgia

A highlight of the day was the testimony shared by one father, giving a firsthand account of his family’s experience living with CAH in Fiji. Mr Cacgia, a school teacher and devoted father of four (two of whom live with CAH), courageously shared insights with guests on the challenges experiences, but also the strengths gained by his family through their journey living with CAH. The challenges shared included the external stigma and judgments that can come from well-intended family and community members and the strain this places on marriages and family dynamics. With regard to strengths, Mr Cacgia spoke of the way family



Fig 5: Fiji World Children’s Day Event

and wider community members give support; how the experiences of caring for children with CAH helped his wife find employment; and the way his younger son has grown and been inspired by watching his sister’s journey. His testimony also highlighted gaps in teacher first - aid training and his ambition for change.

This testimony of lived experience provided great encouragement to the CAH community, exposed the true struggles of living with a chronic condition in countries like Fiji, and inspired hope in all who heard.

Building the CAH Community in Zimbabwe

Trudy Nyakambangwe

Social Scientist & Rare Diseases Advocate

PhD in Child-Sensitive Social Policy



Introduction to Zimbabwe

Trudy began by introducing the work being done by the CAH community in Zimbabwe to support themselves. She highlighted the patient-led model of their work, which is so powerful because the community knows what is most needed and suitable for themselves.

Situational context of Zimbabwe:

- A country in Sub Sahara Africa
- Capital city: Harare
- Population of 16 million
- Low-middle-income country
- Primary health care model

The team in Zimbabwe have been working with CLAN's 5 pillar model in all their programs and activities, and Trudy shared updates relevant to each pillar in turn.

Pillar 1 - Essential Medication and Equipment: Available and Affordable

Thanks to the support of CLAN the Community has received a free supply of Hydrocortisone and Fludrocortisone for the past two years. This supply has allowed them to have a smooth process of caring for the CAH community early on, however they are now waiting for another batch to come through and the delays are stressful. Despite this, during this waiting period, they have experienced amazing support within the community itself, with some families with greater access to medicines giving to those who do not have and supporting them. The team is also lobbying for the addition of Fludrocortisone on the essential drugs list, so that it might become more accessible and affordable.

Pillar 2 - Education, Research and Advocacy

A number of activities have been held over the last three years, most recently holding a Rare Disease Day event in early March where doctors and policy makers were present to answer the community's questions. Other work has included: the distribution of appropriate educational material; webinars and workshops for healthcare professionals, community members, and policy makers to learn more about rare diseases; the creation of a patient database for CAH; and activities to raise awareness through social media.

Pillar 3 - Optimal Medical Management

In response to low levels of awareness among health professionals and the high child mortality that resulted, a small medical alert information card was created and distributed to CAH community members for them to take with them to health facilities in the event of illness or adrenal crisis. There has also been training on crisis management and mental health and wellbeing, with strong efforts to build rapport with multidisciplinary health professionals and stakeholders.



Fig 6: CAH Medical Alert Information Card

Pillar 4 - Encourage and Empower Rare Diseases in Zimbabwe Support Groups (RDZSG)

Support group members have been providing important help to one another and valuable relationships have been formed among families. Three more families have joined the support group over the last year and have noted feeling that the group is like a big family because they are all experiencing the same issues. The groups help to reduce isolation and stigma, and also empower the members to face challenges and stand up for their rights. Sessions are held both online and in-person, with specialists regularly invited.



Fig 7: CAH Support Group Meeting in Zimbabwe

Pillar 5 - Reduce Financial Burdens of Rare Diseases that lead to Poverty

CAH is a lifelong condition which can lead to financial burdens being placed on families without medical aid coverage. To address this issue, income-generating projects have been created to empower families, such as a poultry project that was run last year. Partnership with other organisations have also allowed training and women's empowerment projects to be provided, such as financial literacy education. Additionally, a health fund has been set up for families to access during hospitalisation.

Overall reflections on successes and achievements

- Reduced mortality rate – no children diagnosed with CAH have died since this project began
- Empowered families
- Increased knowledge of CAH – for families and health professionals

Challenges

- Regulatory challenges in terms of getting medication into Zimbabwe
- Limited availability of medication in pharmacies
- High cost of medication
- Limited funding
- Under-staffing in specialist care

Living with CAH in the Philippines

Jeff Cagandahan

President and Co-founder of Intersex Philippines
Co-chair of Intersex Asia



Issues faced by the CAH Community

Jeff spoke at this event as a leader of the Asia Pacific intersex community, and as a person who was born with CAH. Issues identified as commonly affecting persons living with CAH in the Philippines included:

- Challenges with birth registration
- Bullying and discrimination in schools
- Difficulty in getting a job
- Lack of awareness
- Need for strong healthcare policy
- Difficulty in accessing medicines and medical laboratories

HB No. 9555 - The Cagandahan Bill

Jeff petitioned the Supreme Court in the Philippines, and in 2008 was granted permission as the first person in the country to officially change his name and sex marker. He then decided to draft a bill so that the rights of all members of the Intersex Community might be protected. IHB No. 9555 or “The Cagadahan Bill” is an act further authorising the city or municipal civil registrar and the consul general to change the sex and the first name of an Intersex person appearing in the civil register without the need of a judicial order. The bill was filed in Congress in November 2023 and is awaiting approval.

Access to Medicines

CAH is listed at the top of the list of rare diseases acknowledged by the Department of Health in the Philippines. The ‘Rare Disease Act of the Philippines’ (Republic Act 10747) provides that is the duty of the State to protect and promote the right to health of the people, including the right of persons living with rare diseases to survival and full and healthy development as individuals through access to timely health information and adequate medical care. Despite this, access to medicines remains a significant issue for people living with CAH in the Philippines. To date, there is only one pharmaceutical company that supplies most of the medicines for those with CAH (both fludrocortisone and hydrocortisone), and this supplier is based in Metro Manila. Thus, access to medicines and treatment for those in rural and remote areas is a significant barrier. Jeff frequently hears from CAH Community members who struggle to access the medicines they need to survive and thrive.



Intersex Philippines

After receiving significant support from the community for his petition to the Supreme Court, Intersex Philippines was founded with just three members. There are now more than 300 members from across the country, including people living with CAH, as well as their families. To address the lack of education and awareness that exists, the organisation has put together resources such as animated videos, awareness campaigns, youth empowerment programs, and capacity training. They also recently produced a coffee table book, titled 'I Exists'.



Fig 8: Intersex Philippines coffee table book

Research and Action for CAH in Sri Lanka

Sumudu Seneviratne

Professor in Paediatric Endocrinology – University of Colombo
Honorary Consultant Paediatric Endocrinologist – Lady Ridgeway
Hospital for Children



Introduction to Sri Lanka:

To provide some background, Dr Sumudu began by giving some basic demographic information about Sri Lanka and CAH statistics:

- Sri Lanka is ranked as a LMIC in South Asia
- Population: 22 million
- Estimated prevalence of CAH: 1 in 12, 350
- No Newborn Screening for CAH

The first Paediatric Endocrine clinic in the country was established in 1999 at Lady Ridgeway Hospital for Children, Colombo. Dr Sumudu's presentation was based on her research and experience with this cohort of patients over this last 25-year period.

Status of children with classical CAH over two decades (1999-2018) in the absence of NBS:

Presenting status of children with classical congenital adrenal hyperplasia over two decades (1999–2018) in the absence of newborn screening in Sri Lanka

Sumudu N. Seneviratne, Udara Sandakehera, Chaminda H. Jayawardena, Ashangi M. Weerasinghe, Piyumi S. Wickramarachchi and Shanya de Silva



- Mean age at diagnosis was 20 days
- > 80% of these patients already had an impending adrenal crisis at the time of diagnosis.
- Gender disparity in age of diagnosis:
 - Mean age for girls: 10 days
 - Mean age for boys: 30 days
- Male to female ration: 0.4:1 (it can be assumed many boys died from CAH that was not diagnosed)
- Higher rates of CAH in ethnic minority groups (50%)
- Parental consanguinity (27%)
- Family history (17%)

There were also significant challenges experiences by girls with CAH due to in-utero virilisation:

- 96% had virilised genitalia (50% with severe virilisation)
- >50% faced gender uncertainty at birth
- 10% experienced gender misidentify
- >60% developed hyponatremia prior to diagnosis and treatment

Improving CAH diagnosis in Sri Lanka:

Dr Sumudu explained how the results of this research confirm the urgent need for newborn screening for CAH in Sri Lanka. However, due to economic constraints this has not been feasible at the present time. Educational efforts that have been implemented to help reduce mortality and morbidity in children with CAH in Sri Lanka include:

- Educating families who have a child living with CAH (through leaflets)
- Educating health staff at delivery units and the public health community midwives to recognise early signs of CAH, through the Family Health Bureau
- Educating high risk communities

Gender-Based Issues in Girls with CAH

The team conducted an outcomes survey with girls who had undergone surgery for significant genital virilisation:

- Median age at surgery: 3.5 years (range 1 - 12.5)
- Pre-operative state: Prader stage 3 and 4
- High parental satisfaction (>70% agreeing surgery reduced psychosocial issues and anxiety)

A Gender Identity Questionnaire for Children was translated into local languages and used as a tool to assess gender-role behaviour and gender identity in girls with CAH. The study found that girls with CAH had lower scores than children without CAH, which indicated atypical gender-role behaviours. These findings are important for health care providers to be aware of when they care for girls with CAH and demonstrate the need for multi-disciplinary care as well as greater psycho-social support, such as through support groups.

Quality of life in children and adolescents living with CAH

The global literature shows that in both high- and low-income countries, children and adolescents living with CAH experience impairments in their psycho-social as well as physical quality of life. In Sri Lanka, this experience is more usually the case for girls than boys. Other factors associated with lower quality of life were poor compliance with medications and ethnicity – with poverty, inequity and structural barriers all underlying causes. These findings highlight the importance of family support groups, and systems reform to improve equitable access to medicines and quality care.

Treatment and Management of CAH

Long-term medication (Hydrocortisone and Fludrocortisone) has been available for many years in Sri Lanka in tertiary care government hospitals. However, since the 2022 economic crisis many people have been experiencing reduced availability of these medications. Sumudu expressed thanks to CLAN for their recent medicines donation that has meant that all of their children have been able to continue their treatment through this time.

For management of adrenal crisis, an educational leaflet has been produced, as well as a laminated steroid alert card which can be carried wherever families go.

To address the issues associated with gender mis-identity at birth and erroneous birth certificates, work is being done with the help of the Asia Foundation to create a simpler system to access a clear birth certificate from the Registrar department. Additionally, the Centre for Complex Hormonal Disorders in Sri Lanka has been established with the aim of improving clinical care, enabling greater collaboration and advocacy, and improving community awareness and social support. Ongoing efforts are underway to scale NBS.

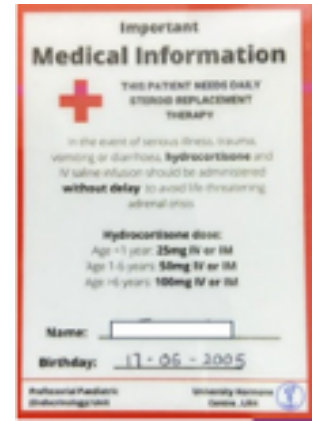


Fig 9: Steroid Alert Card

Upcoming Initiatives

1. Establish a CAH support group in Sri Lanka
2. Translation of "A Book for Young Women with Congenital Adrenal Hyperplasia" (Indonesia) to local languages (Sinhala and Tamil)
3. Sharing resources: Clinical profile book for CA



Fig 10: Clinical Profile Book for CAH

Translated from Bahasa Indonesian to English, 'A book for young women with Congenital Adrenal Hyperplasia' is proving a powerful resource for Community members, and will soon be adapted for use in Sri Lanka.

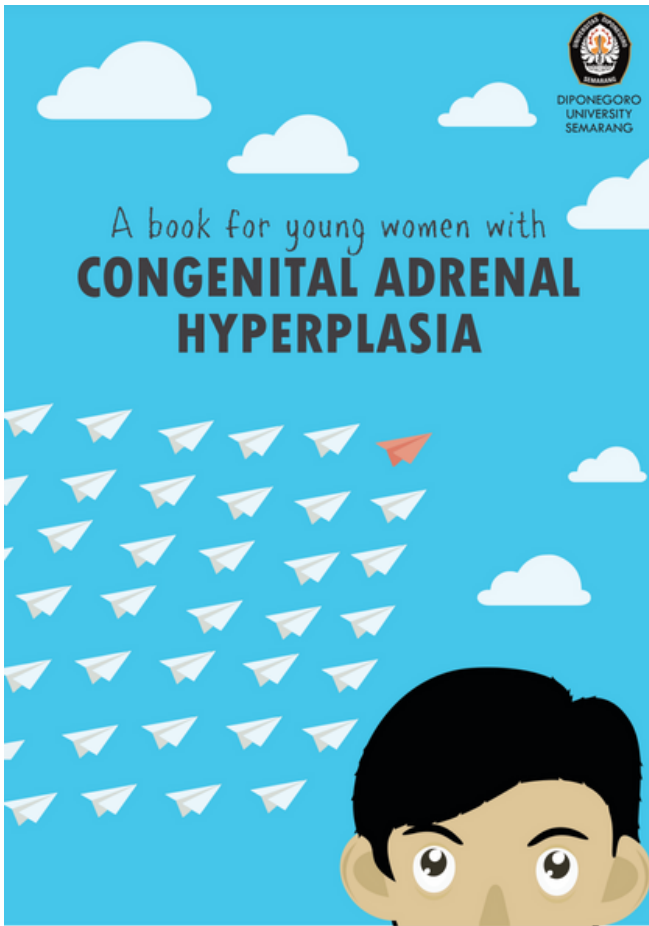


Fig 11: Screenshots from 'A Book for Young Women with Congenital Adrenal Hyperplasia'

An update on CAH in Indonesia

Agustini Utari

Consultant Paediatric Endocrinologist & Head of the Paediatric Endocrinology Division - Diponegoro University
Dr. Kariadi Hospital Vice president of GPED



Introduction

Dr Agustini began by discussing the importance of early diagnosis of CAH, stating how delayed diagnosis may lead to serious clinical consequences which can impact longerterm health outcomes and patient survival. If left untreated, CAH may be fatal or be responsible for long-term consequences and psycho-social problems. In developing countries with limited resources, such as Indonesia, there are numerous challenges which need to be overcome due to the lack of newborn screening for CAH and limited access to medications.

Introduction to Indonesia

- 17,000 islands, 514 districts/cities, 34 province
- 39 paediatric endocrinologist + 14 fellows available in only 17 provinces
- Population: 278 million people
- 4.8 million babies born each year

Indonesian Paediatric Society Registry of CAH

The Indonesian registry identified 439 patients with CAH between 2009-2020. However, with the global incidence being at 14-18000 live births, it is estimated that Indonesia should have an incidence of more than 300 newborns with CAH every year. Thus, it is assumed that many cases are going undetected and that there are high rates of mortality as a result of adrenal crisis.

- In 2009 there were 69 children on the Register (M:F ratio 1:4)
- In 2020 there were 439 children (M:F ratio 1:2.2)

In an ideal world, the M:F ratio for the CAH Community should be 1:1. Dr Agustini explained the lower male:female ratio for CAH in Indonesia is likely to be the result of the absence of a newborn screening program in Indonesia, resulting in a lack of diagnosis and so higher mortality for males as they do not present with atypical genitalia. Whilst the M:F ratio has improved over time, there is still a clear and urgent need for NBS for CAH.

Mortality in CAH Patients

The situation before 2016, when hydrocortisone was not yet readily available in Indonesia, showed that, out of 78 patients in the CAH cohort:

- 12.8% were reported deaths due to adrenal crises
- Only 5% are 46 XY CAH (ie not 50%): This may indicate that adrenal crisis in male newborns are under- diagnosed or unidentified.
- 9 siblings of 7 families had a history of siblings who died because of a salt losing crises before diagnostic confirmation

Problems in Indonesia

Diagnosis:

- No newborn screening
- Lack of knowledge about CAH
- Late identification of disease
- Late referral
- Late diagnosis
- Limited laboratories
- 17 OHP not covered by health insurance

Access to Medicine:

- Life-long treatment needed
- Hydrocortisone available since 2018 - now covered by government health insurance
- Fludrocortisone (FC) only available since August 2023

Access to Medicine

Fludrocortisone is now available and manufactured in Indonesia through the Sydnacort company. The journey to see this medication available in Indonesia has been lengthy with product development beginning back in 2018 and being completed in 2020. A bioequivalence study was performed in March-April 2021, and the product was registered in June 2023, before finally launching in August 2023. However, Fludrocortisone is not yet included in the national essential medicines list and so is not yet covered by the national health insurance in Indonesia.



Fig 12: Image of Fludrocortisone medicine (Sydna farma)

Progress of Newborn Screening Program in Indonesia

The Indonesian government is expanding the national NBS program, which has resulted in great increases in the rates of NBS for Congenital Hypothyroidism. The government introduced a national policy mandating NBS provision before health workers could claim delivery rates from the national health insurance. Since this policy was launched in September 2023, the NBS rates have significantly increased. Before then, coverage was at around 3% but by December 2023, 28% of newborns had been screened. The Ministry of Health is now aiming to reach more than 80% coverage in 2024. Additionally, there are plans to add CAH and G6PD screening to the national NBS panel.

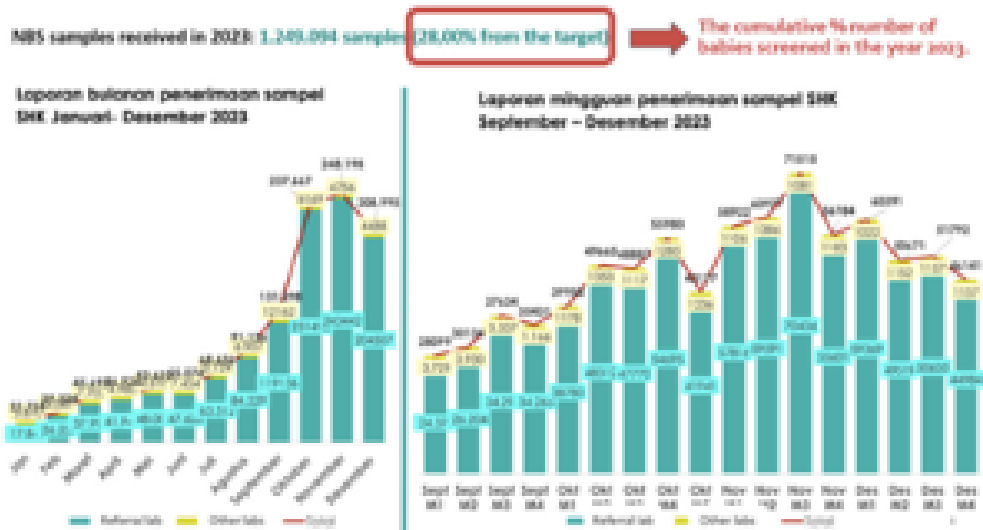


Fig 13: Progress of NBS in Indonesia in 2023

A pilot project for CAH NBS has now been launched in Indonesia. In October 2023 the Ministry of Health and the National Newborn Screening Expert Working Group began discussions, with guidelines for the pilot project being produced by December. In April 2024, the NBS pilot project will begin for CAH in Indonesia. The project will cover 77 districts and include four referral laboratories across Java.

Plans for the Future:

1. To propose the addition of Fludrocortisone to the National Formularium (FORNAS) as an essential medication, so that it can be covered by Government health Insurance (BPJS)
2. Establishing CAH NBS for larger coverage across Indonesia

The Colombian CAH Community Unites for Change

Paola Duran Ventura

Chief of Pediatric Endocrinology - Fundacion Cardio Infantil,
Bogota Colombia
Director of SiEndo Foundation



Introduction to Colombia

- Upper middle-income economy
- GDP per capita: \$6,421
- Infant mortality rate: 11.04 deaths per 1000 live births (2023)
- Under 5 mortality rate: 13 per 1000 birth (2021)
- LAC (Latin America and the Caribbean) is the world's second most unequal region and Colombia is the most unequal country in the LAC region

Overview of Collaboration with CLAN

- In March 2023: CLAN collaboration began. Paola shared that CLAN has been an inspiration, mentor and guide along the way, with bi-weekly Zoom meetings between CLAN (Dr. Kate Armstrong, Catherine Cole and team) & Colombian team (Johanna Hjerthen, Cristina Ruiz, Dr. Paola Durán)
- CLAN has generously shared its expertise and knowledge, including extremely valuable tools.

Health Needs Assessment (HNA) Survey

A Community Survey template was developed for Colombia based on a number of templates including:

- a) Survey for consulting families attending NS Club Meetings (Dr. Kate Armstrong thesis)
- b) Interview guide for consulting with families of children living with NS (qualitative focus) (Dr. Kate Armstrong thesis)
- c) CHECC (Child Health Equity Checklist Count) Scorecard, Will a child survive & thrive with a chronic health condition in a resource-poor setting? (Dr. Kate Armstrong thesis)
- d) Vietnam Publication 2006. (Armstrong et al)
- e) Fundación Fiambre Health Brigade survey - August 24, 2022

The adapted survey for Colombia included 112 questions in Spanish, was aimed mostly at caregivers, and had a focus on CAH. It was initially piloted with 6 patients living in Bogota and in rural areas relatively close to the capital city, before being scaled for use at the inaugural CAH Club meeting.

Colombia's 1st CAH Club Meeting: 10th March 2024

Key partners:



Preparation and implementation of the Club meeting focused on CLAN's five pillars

Pillar 1 - Access to Medication and Equipment

- Since December 2023, Fludrocortisone and Hydrocortisone have been included in the national list of essential medicines
- These medicines are available but not always guaranteed due to barriers in the health system

Pillar 2 - Education, Research and Advocacy

- The team ran education sessions in Spanish
- Gave materials and links to the children (E.g. instructions on how to behave when they have to take sick days)

Pillar 3 - Optimal Medical Management

- A social worker assisted in communicating to the families about how to navigate the Colombian health system and where to find solutions in situations where they could not access medical clinics.

Pillar 4 - Encourage Family Support Groups

- 111 people (patients and family members) attended
- All 32 families completed the HNA
- A testimony was presented by Juan Pablo López, a 20-year-old medical student living with CAH. His story inspired all the young children and gave them hope.



Pillar 5 – Reducing financial burdens

·A flyer was shared with families, with details on how to access support

Key initial responses from children and families:

Dr Paola shared that what they saw most from this meeting was that families need to be heard. The families expressed gratitude for the first opportunity to meet and get to know each other. The meetings agreed to the creation of a support network, thanks to four families who volunteered to lead this.

A Colombian CAH community has now been born. The young people have now created a social media community on Instagram to connect with each other (#HSCUNIENDOFUERZAS)

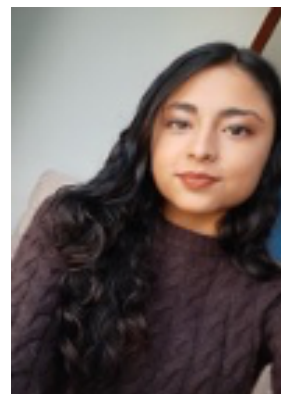
The main concerns that were identified through the questions from families were to do with a lack of education, particularly around the emergency injection and understanding the genetics. Access to medication was also raised as a concern as there is still restricted access due to system operational issues that mean access is not guaranteed. Regular advocacy is important to ensure this access.



Living with CAH in Colombia

Anghela Castro

CAH community representative



Anghela is 17 years old and lives with CAH in Colombia. She is an entrepreneur with her own clothing brand, and intends to start studying fashion design at the Jorge Tadeo Lozano University in Bogotá.

Attended the first CAH club meeting in Colombia

Living with CAH in Colombia

Anghela shared in Spanish about her experience living with CAH in Colombia, and Dr Paola translated.

When Anghela was 8 years old she had an adrenal crisis at school, but nobody knew how to deal with it. She almost fainted and was feeling very unwell, she spoke to the teacher, but she couldn't help her and sent her to the school reception to wait for her mother or someone to come and help her. She had to face this all by herself, even though her mother had been to the school to tell them about her condition, apparently they hadn't taken it seriously. When my mother arrived she gave me the oral medication, because in Colombia we do not have the emergency injection to carry with us at all times. Her mother took her to the nearest hospital, but they didn't know how to handle her condition or didn't understand. So, her mother decided to take her to a hospital where she could feel safe, which was 17km away from her house and took them an hour to get there.

Today, at 17 years old when Anghela looks back, she now understands better everything that happened and that she is very privileged to have a mother who is a nurse, who learned about her condition, and has helped her live a good life with CAH. She said "I understand that is not the same for everybody in Colombia, if I had been in another place and had not had the help of my mother, it would have been different, and my story could have been worse."

Anghela attended the first CAH club meeting in Colombia and was able to meet other children and adults with CAH, and now says she understands "all the work we have to do, all the education, and everything we have to do to help everybody have equity to have the same opportunities in Colombia."

Anghela concluded her presentation saying...

"Today I want to raise my voice for all the children that live with CAH in Colombia, so we can all have the same opportunities and so we can all have access to education to live a good life with dreams, with goals, and to receive and give all the love we want to give"

[Please watch Anghela's powerful video sharing her reflections on the meeting here...](#)



Concluding comments and reflections

CLAN is extremely thankful to all of our esteemed speakers for so generously contributing your expertise and experiences to this event, and for the support of all @MATES4Kids participants for your support and commitment to working collaboratively to reduce the preventable mortality associated with CAH by 30% by 2030.

This event was an important step in addressing what actions are needed to accelerate gender equality and empowerment for the International CAH Community. We were able to share and learn about the differences and inequities that exist between countries, and hear more about the breadth and depth of the experiences of people with CAH across the globe - particularly girls, women and people born biologically female with CAH. It is clear that there is still a great deal to be done in order to improve health and wellbeing outcomes for people living with CAH in resource-poor settings, to see them live happy and healthy lives on par with those in high resource settings.

At this CSW68 event we saw the importance of newborn screening, access to medicines, and strengthening communities in moving toward achieving the SDG's by 2030. The event's discussions were specifically focused on SDG 1 (No Poverty), SDG 3 (Good health and wellbeing), SDG 5 (Gender Equality), and SDG 17 (Partnerships for the goals).

To stay up to date with the activities of @MATES4Kids, please subscribe to the WHO KAP, visit the CLAN and @MATES4Kids websites, or follow us on social media, where you can find us on most platforms. Please don't hesitate to get in touch to learn more about the work that CLAN and @MATES4Kids do.

We look forward to continuing to work together as we journey towards 2030. Let's strive to make essential medicines, newborn screening and strong community support accessible to #EVERYchild living with CAH so that together, we #LeaveNoChildBehind.

In-person participation at #CSW68 by CLAN's UN Youth Representative

My name is Katie Blomkvist. I am a Master of Public Health Student at Lehigh University and a United Nations Youth Representative for CLAN. On Wednesday, March 20th, I had the opportunity to go the United Nations alongside other passionate students and faculty to attend NGO CSW events.

The first event attended was organized by the Widows Development Organisation (WiDO). WiDO is one of Lehigh's UN accredited NGO partners. We were joined by Dr. Elanor Nwadinobi, WiDO's president and member of the Lehigh College of Health Dean's Advisory Council.



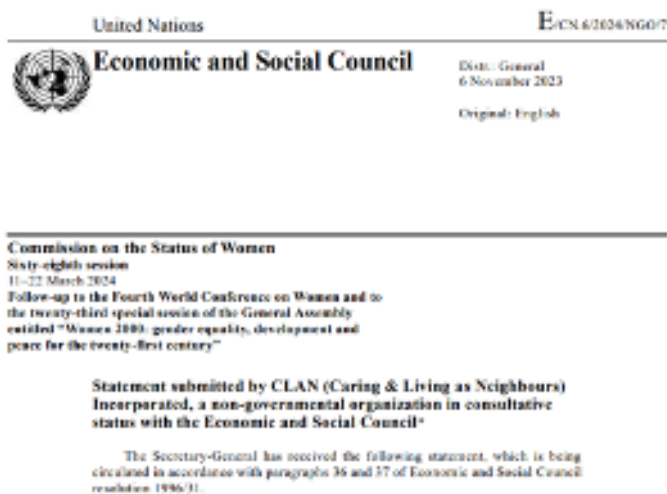
WiDO is based in Nigeria and was founded in 1996. With a motto of “Unity, Love, & Industry,” WiDO’s mission centers on raising awareness about the challenges widows face and improving their social status. Key objectives include advocating for widow’s rights, sensitizing the public, offering educational support for widows’ children, providing counseling services, and collaborating with other organizations. WiDO also focuses on various areas such as legal awareness, income generation, healthcare, and environmental conservation. Through unwavering dedication and passion, WiDO continues to make a positive impact on the lives of widows and their communities.

Dr. Nwadinobi and WiDO team members presented “Feet on the Ground: Achieving Greater Economic Empowerment for Widows”, which focuses on the critical need to support widows globally, particularly in regions where they face marginalization. We heard stories of how widows can be treated in Nigeria, stigmatizing them and referring to these women as “witches” and accusing them of their husband’s deaths. Widows can undergo a process of drinking water used to cleanse their husband’s corpse to prove she was not responsible for her husband’s death. Widows can struggle to be financially stable after their husbands pass, which can create further health challenges for the family. Stories like these demonstrate the need for organizations like WiDO.

The second presentation I attended was titled “Economic Empowerment of Women Entrepreneurs: Gender Equality and Development Goals.” This presentation showcased leaders from various corners of the globe, representing countries such as Turkey, the USA, Australia, Iran, Sudan, Uganda, Lebanon, and the UK. Each speaker highlighted different initiatives their organizations are tackling to empower girls and women towards financial independence.

Overall, my experience attending NGO CSW in person was incredibly inspiring. Witnessing many powerful women from around the globe gathering to share their stories was moving. This event marked my first in-person attendance at a UN event. Seeing the faces of women who are making significant impact on the lives of women and girls worldwide was enlightening. It reinforced the importance of collaboration in effecting the change we want to see in the world.


Appendix 1 - Full text - CLAN's Written Statement for UN CSW68



CLAN (Caring & Living as Neighbours) supports the sixty-eighth session of the Commission on the Status on Women (CSW) and its mission to improve gender equity as outlined in the Beijing Declaration and Platform for Action (BPfA) in 1995. CLAN would like to acknowledge the Wallumedegal peoples of the Eora Nation, the Traditional Owners of the land on which we are headquartered. CLAN also acknowledges the Lenape people, on whose Land the United Nations is headquartered in New York City, and we pay our respects to Elders past, present, and emerging.

CLAN is an Australian non-governmental organisation (NGO) founded in 2004. CLAN's mission is to maximise quality of life for children living with non-communicable diseases and other chronic health conditions in resource-poor settings. According to the World Health Organization, a non-communicable disease is a long-term, non-transmittable disease that results from genetic, physiological, environmental and behavioural factors. Non-communicable diseases cause 24.8 per cent of disability-affected life years and 14.6 per cent of deaths among children and adolescents. In addition, the Centres for Disease Control and Prevention states that non-communicable diseases account for 41 million deaths each year with about 85 per cent occurring in low- and middle-income countries. With vulnerability of age and socioeconomic factors combined, children living with non-communicable diseases and other chronic health conditions in resource poor settings are at especial risk of preventable mortality and morbidity.

CLAN operates under a rights-based, strategic framework for action that promotes a community development approach to redressing inequities for children living with non-communicable disease in resource poor settings. CLAN seeks to facilitate multisectoral, collaborative efforts focused on five pillars that families have



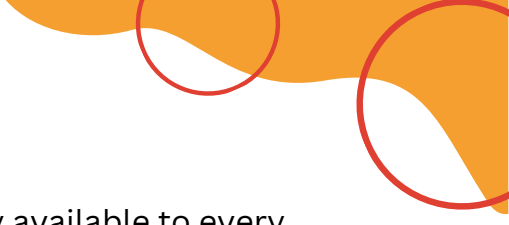
told us are essential to achieving the highest possible quality of life for their children:

- Affordable access to essential medicines and equipment
- Education, research and advocacy
- Optimisation of medical management
- Encouragement of family support groups
- Reducing financial burdens and promoting financial independence.

Delays in diagnosis and limited access to affordable medicines, equipment, quality healthcare, social services and support are especial challenges facing children living with non-communicable disease in resource poor settings. Early diagnosis and optimal management of childhood non-communicable diseases dramatically improve health outcomes and quality of life – not just in childhood, but across the life-course.

Universal access to Newborn Screening has a vitally important role to play in diagnosing many childhood non-communicable diseases at an early stage. Newborn Screening is a vital public health innovation that was first made available in the 1960s. Newborn Screening tests have the potential to diagnose conditions requiring urgent (yet affordable) treatment to prevent profound developmental delay, disability and even death, thereby helping to redress preventable childhood mortality and morbidity. In virtually all high-income countries every newborn child has a simple heel-prick blood test (used to screen for conditions such as Congenital Adrenal Hyperplasia, Congenital Hypothyroidism, Phenylketonuria and Cystic Fibrosis), hearing tests and pulse oximetry (to screen for Critical Congenital Heart Disease), with treatment started as early as possible once a diagnosis is confirmed, thereby optimising health outcomes.

By contrast, Newborn Screening of any description is rarely available in lower income countries. Conditions that are easy and cheap to treat go undiagnosed and preventable mortality and morbidity are high. Girl children in these countries are at especial risk. According to the National Institute of Health (NIH), women in lower income countries suffer from higher levels of economic hardship and gender inequality than in economically advanced countries, which results in poorer health outcomes. The evidence shows women and girls too often have less access to care, and when they do, they often receive less aggressive treatments, thereby increasing their risk of complications and denial of their basic human rights to life and health. Women also are more likely to end up as sole carers for children with special health needs, and this further impacts on their financial wellbeing.




It is unacceptable that Newborn Screening is not universally available to every newborn child. Newborn Screening overcomes gender inequities. Universal Newborn Screening programs do not discriminate against girl babies and have the potential to cut through the social, cultural, and economic determinants of health. Newborn Screening must be scaled and made available to all as a matter of urgency if we are to achieve the United Nations' Sustainable Development Goals (notably SDG 3.2.1, 3.2.2 and 3.4). Newborn Screening meets World Health Organization screening criteria, and is low-cost, effective, acceptable, available, and safe. The technology is proven, and has only to be scaled appropriately to cover those living in the most vulnerable circumstances.

Universal Health Coverage will be key to scaling Newborn Screening, and making it available to all children around the world. Cost benefit analyses have clearly demonstrated the value of Newborn Screening, and administrations that choose to cover the costs of the essential equipment, medicines, workforce and structures required to implement Newborn Screening would reap the benefits in terms of reduced mortality, morbidity and disability. With affordable access, families in vulnerable situations will be less likely to experience catastrophic health spends; and will have greater chance of avoiding life and death decisions about how to spend limited resources. Optimal treatment of childhood non-communicable diseases during the “golden years” of early and rapid growth and development would give more children the opportunity to enjoy their rights to life and health and achieve their full potential.

CLAN is proud to serve as Secretariat for @MATES4Kids, a global coalition seeking to reduce the preventable mortality associated with childhood non-communicable diseases in low- and middle-income countries. Starting with congenital adrenal hyperplasia as a pilot condition, the @MATES4Kids movement is committed to reducing the preventable mortality associated with congenital adrenal hyperplasia by 30 per cent by 2030. It proposes to achieve this through collective and collaborative focus on three objectives: improving affordable access to essential medicines and equipment; strengthening affected communities; and scaling Newborn Screening.

CLAN and the @MATES4Kids movement are committed to redressing inequities for children living with chronic health conditions in partnership with our national and regional communities, the Commission on the Status of Women, UN Women, the WHO, and other relevant United Nations entities. The international community has a tremendous role to play in ensuring children living with noncommunicable diseases in resource-poor countries of the world enjoy a quality of life on par with that of their neighbours' children in wealthier countries.



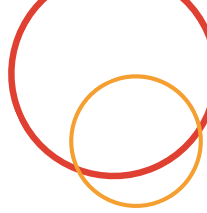
Newborn Screening must be seen as a vital component of a holistic, health-system strengthening approach. A community development approach to the establishment of screening programs will address poverty and gender inequities, and will require countries to ensure the needs of all children diagnosed with chronic conditions can be met. This includes securing access to essential medicines and equipment; investing in training and education for workforce, families and the broader community; and establishing financial protection mechanisms.

CLAN emphasises the crucial point that all children have a right to health and life and no child or family should ever face the threat of disability or death due to economic and gender inequities. This mission aligns with the standards established by Beijing Platform for Action and takes account of the sixty-eighth session of the Commission on the Status of Women's priority theme of "accelerating the achievement of gender equality and the empowerment of all women and girls by addressing poverty and strengthening institutions and financing with a gender perspective". CLAN would like to especially underscore the vital role Newborn Screening technology must play as an essential component of any effective health system, noting its capacity for promoting equal, timely and affordable access to treatment for women and girls.

CLAN calls upon the Commission on the Status of Women, UN Women, and other relevant United Nations entities to acknowledge the essential role Newborn Screening must play in providing early diagnosis and treatment for women and girls living with non-communicable diseases. It is essential to increase the span of Newborn Screening globally. The technology already exists and has been proven reliable and cost-effective – now it needs to be made available to all. Innovations such as Newborn Screening and universal health coverage do not discriminate against women and girls and should be made available to #EVERYchild so we #LeaveNoChildBehind.

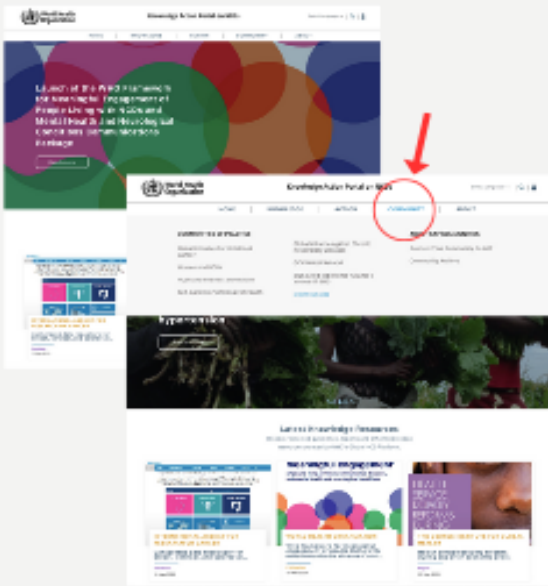
CLAN reaffirms its commitment to eliminate gender inequality in accordance with the Commission on the Status of Women and Beijing Declaration and Platform for Action. We believe women serve as vital agents of change and recognise the indispensable need for women's empowerment in order to accelerate the UN Sustainable Development Goals and champion the values of UN Women.

Appendix 2 – Guide to Joining the @Mates4Kids Community of Practice on the WHO Knowledge Action Portal



Joining the @Mates4Kids Community of Practice on the WHO Knowledge Action Portal

@MATES4Kids uses the World Health Organization's Knowledge Action Portal (KAP) on NCDs as the primary platform for connecting our Community of Practice (CoP). It will facilitate seamless collaboration and regular dialogue between our global network of stakeholders to drive practical action. Topics of discussion will especially relate to improving access to essential medicines, strengthening community development, and scaling newborn screening (NBS). 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. We invite you to join using the instructions below!



Step 1. Access the WHO Knowledge Action Portal via:
<https://www.knowledge-action-portal.com/>
Click on "COMMUNITY" and select "@MATES4Kids"

We encourage you to explore the KAP and visit other communities as well!

Step 2. You need to sign up to the Knowledge Action Portal (KAP) in order to access the communities – please click "Create new account"

Sign up to the KAP with your email address and create a password. A moderator will approve your account - this should not take more than 1-2 working days. Please email emma@mates4kids.org if you have any difficulties.

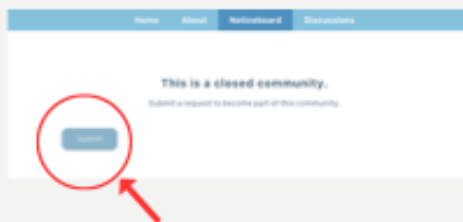
You will receive an email when your KAP account is approved.





As a general KAP user, you can view the community home page and about page.

If you wish to access the noticeboard or discussions, you need to join the community. We hope that you will want to join the community so that you can get the most out of the networking and knowledge sharing opportunities.



If you want to join the community to view these "closed" areas, please click on "Submit" to become part of the community.

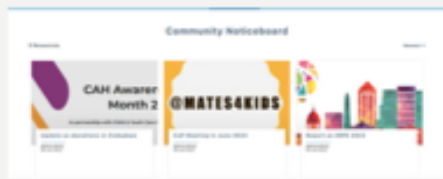
Again, this requires approval by a moderator – please contact us if you have any difficulties.

Once approved you will receive an email confirming that you are a member of the @MATES4Kids community.

So now that you have joined the @MATES4Kids community, you are able to get the most from the networking and information-sharing opportunities on the KAP...

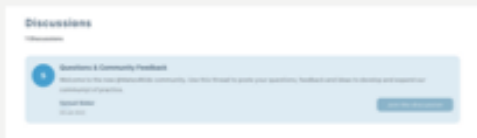


The home page shows an overview of each subsection, and includes a calendar of events, with links for further information and registration.



The noticeboard shares news from community members and information about upcoming events, learning opportunities, funding opportunities.

Please let us know if you have any messages or content you would like to share with the @MATES4Kids Community of Practice - we will be pleased to include it on our noticeboard!



The discussion threads can be used to connect with other community members.

Please contact emma@mates4kids.org for assistance!



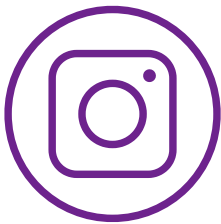
CLAN Child Health



CLAN Child Health



@clanchildhealth
@mates4kids



@clanchildhealth
@mates4kids



www.clanchildhealth.org
www.mates4kids.org



info@clanchildhealth.org



Caring & Living As Neighbours

