EVERYONE INCLUDED

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

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 Lehigh University United Nations Youth Representative Nicole Pasterczyk and @MATES4Kids Project officer Katie Blomkvist, 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:

- YKAG (Yayasan Kesehatan Anak Global)
- The Indonesian Ministry of Health
- University of Indonesia
- International Pediatric Association
- SLEP (Latin-American Society of Pediatric Endocrinology)
- SiEndo
- National Institute of Pediatrics, Mexico City
- Lady Ridgeway Hospital for Children, Sri Lanka
- International Society for Neonatal Screening

Table of Contents

List of Abbreviations

Abbreviation	Full text
CAH	Congenital Adrenal Hyperplasia
CLAN	Caring & Living as Neighbours
CSocD62	62nd Session of the United Nations' Commission for Social Development
IPA	International Pediatric Association
MATES4Kids	Maximising Access To Essential Supplies for Children
NBS	Newborn Screening
NCD	Non-Communicable Disease
NGO	Non-Governmental Organisation
SDG	Sustainable Development Goal
UHC	Universal Health Coverage
UN	United Nations

A video recording of the event is available on CLAN's YouTube account here.

Figure 1: Screenshot from United Nations CSocD62 Side Event hosted by CLAN in partnership with @MATES4Kids & Lehigh University on February 6 2024

Executive Summary

CLAN (Caring & Living as Neighbours) was proud to engage in events relating to the 62nd
Session of the Commission for Social Development (CSocD62) in 2024.

The CSoc62 Priority Theme was **“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.”**

CLAN’s goal in engaging in #CsocD for the first time was to support the work of the @MATES4Kids (Maximising Access to Essential Supplies for Kids) movement, and highlight the urgent need to scale Newborn Screening (NBS) as part of a comprehensive and strategic approach to reducing the preventable mortality associated with childhood non-communicable diseases (NCDs) in resource poor countries, and thereby contribute to global efforts to achieve the Sustainable Development Goals by 2030.

The key objectives of @MATES4Kids participating in CSocD62 were to:

1. Raise awareness of the inequities associated with NBS globally, and the role NBS can play in reducing the inequitable and preventable burden of childhood morbidity and mortality by 2030
2. Identify practical solutions, and current successes, case studies, and achievements in the fields of NBS and childhood NCD prevention and management in resource poor settings
3. Provide insights into the economic factors that play in the experiences of the communities of children and families living with childhood NCDs, as well as recommendations for change.

The key recommendations from @MATES4Kids emerging from the activities were:

- Advocate for inclusion of NBS within the Universal Health Coverage (UHC) and Non-Communicable Disease (NCD) discourse (most notably at the upcoming 2025 UN High Level Meeting on NCDs.

- Raise awareness of the rights of #EVERYchild living with NCDs to health and life, and the violations that occur when there is inequitable access to universal NBS

- Raise awareness of the economic and social benefits of NBS

- Showcase and promote healthy public policy and critical action currently underway to scale universal coverage of NBS

- Inform ongoing efforts to improve affordable access to essential medicines and equipment for children living with NCDs in resource poor settings

- Promote community development initiatives and achievements to encourage and inspire others to engage in efforts to ensure the rights of #EVERYchild born with an NCD might be optimally supported and achieve their full potential in life

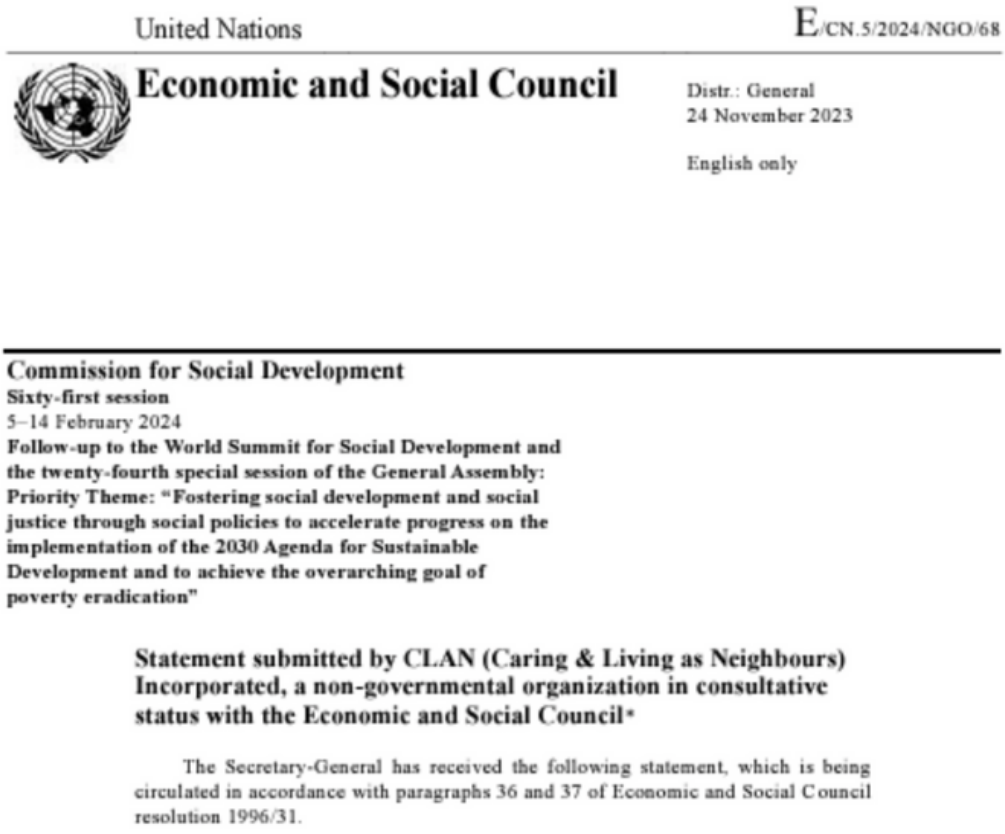
CLAN supported @MATES4Kids participation in CSocD62 through three key activities:

1. Submission of a written statement
2. Delivery of an oral statement by our UN Youth Representative, Nikki Pasterczyk.
3. Hosting a virtual UN CSocD62 Side Event

Advocating at UN #CSocD62

CLAN's Written Statement

CLAN was proud to facilitate submission of a published written statement to ECOSOC that speaks to the vital role NBS can and should play in achieving the SDGs by 2030. The statement is available via the United Nations online, and provided in entirety in Appendix 1 of this report.



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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.

Figure 2: CLAN Official Written Statement Partial Screenshot

CLAN's Oral Statement

CLAN is grateful to have had our CLAN UN Youth Representative, Nikki Pasterczyk, share 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 CSoc62 General Discussion on February 12, 2024 at the United Nations Headquarters, specifically on how NBS promotes health equity regardless of economic status.

A video recording of UN Youth Representative Nikki Pasterczyk's oral statement is available online here. A full transcript of Nikki's Statement is shared in Appendix 2 of this report.

"Newborn Screening can help overcome economic and social inequities as it does not discriminate against babies on the basis of gender, ethnicity or economic status when universally available."

Figure 3. Nikki Pasterczyk sharing her oral statement at UN CsocD62.

A side-event focused on Newborn Screening at #CSocD62

CLAN was proud to host a virtual side event at the 62nd Session of the United Nations' Commission for Social Development (CSoc62) on February 6th 2024, in partnership with @MATES4Kids, Lehigh University, and global changemakers to discuss the role of Newborn Screening (NBS) in promoting economic equity in NCD diagnosis.

The side event was titled *"Newborn Screening: Promoting Equitable Healthcare Regardless of Economic Status"* and brought together experts from around the world to highlight the importance of scaling Newborn Screening to achieve the Sustainable Developments Goals (SDGs), and reduce economic inequalities affecting young children living with NCDs in resource poor settings.

Speakers from Australia, Indonesia, Mexico, Sri Lanka, New Zealand, and the United States of America participated, representing a broad range of NGOs and organisations participating in the @MATES4Kids network to achieve the bold goal of reducing the preventable mortality associated with CAH by 30% by 2030.

CLAN - Lehigh University partnership

This event was hosted in partnership with the Lehigh University United Nations Youth Representative Program. The Lehigh Youth Representative Program started in 2008 where high achieving Lehigh University students are matched with UN accredited NGOs. CLAN is one of 9 NGOs and one of Lehigh's strongest partners. This program allows youth to have a voice in global matters, and in our case, advocacy and action for children who are living with non communicable diseases.

Agenda

Subject	Content	Speaker
Introduction	• Summary of CSoc62 • Introduction of Lehigh/UN partnership • Introduction to Newborn Screening	CLAN – Lehigh UN Youth Representative: Nikki Pasterczyk
@MATES4Kids Introduction	• Rationale for a focus on NBS on the road to 2030	Kate Armstrong
A focus on Indonesia	• Interview & video with Indonesian Minister of Heath • NBS success story from Indonesia	Elizabeth Page Aman Pulungan
A focus on Mexico	• Neonatal screening in Mexico	Raúl Calzada
A focus on Sri Lanka	• Use of CHECC Tool in Sri Lankan setting	Navoda Atapattu
International Society of Neonatal Screening (ISNS)	• ISNS/WHO Update and Discussion	Dianne Webster
Closing Remarks	• Closing discussion and recommendations for next steps	Kate Armstrong

Introduction

Nikki Pasterczyk
United Nations Youth Representative, CLAN

NBS Connection to CSocD62 Priority Theme

At CLAN's first side event at the Commision for Social Development, we presented our session "Newborn Screening: Promoting equitable healthcare for every child regardless of economic status."

We focused on how NBS is a well established technology that has an important role to play in redressing child health inequities globally. When universally available, NBS promotes early and equitable access to diagnostic and therapeutic options for children living with NCDs that could otherwise cause enormous preventable morbidity and mortality. NBS Programs contribute to efforts to achieve the sustainable development goals by 2030, by contributing to health and well being, reducing inequalities, and leveraging partnerships.

What is Newborn Screening?

NBS is a heel-prick method used to obtain blood from a newborn to detect genetic, metabolic, endocrine, and other life-long conditions within a few days of birth. This is pivotal for children with chronic conditions that are important to diagnose and treat within a few days of birth in order to prevent morbidity and mortality. In addition to heel prick tests, NBS can consist of other screening techniques, such as pulse oximetry (to diagnose Critical Congenital Heart Disease) and hearing testing of newborns.

Nikki provided a personal perspective of NBS during the presentation. Her older brother has the genetic disorder PKU, which was detected within several days of his birth in the United States. With NBS, her parents were able to immediately integrate the lifestyle necessary for him to survive and thrive with his condition.

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.

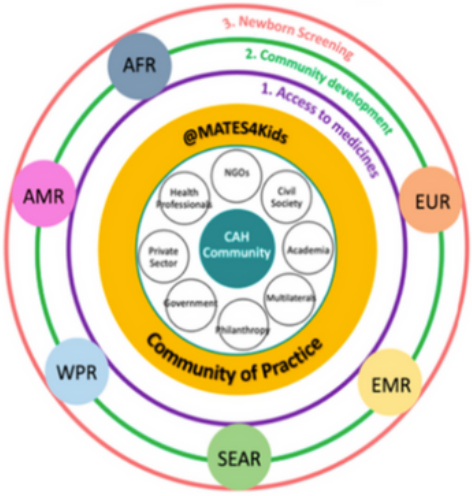
A focus on 30 x 30 x 30

UN CSocD62 celebrates the 30th International Year of the Family. In #IYF+30 @MATES4Kids commits to ongoing efforts to reduce the preventable mortality associated with CAH by 30% by 2030 through collaborative, international action that focuses on:

1. Improving access to essential medicines & equipment
2. Strengthening CAH community development
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 (see figure 4)

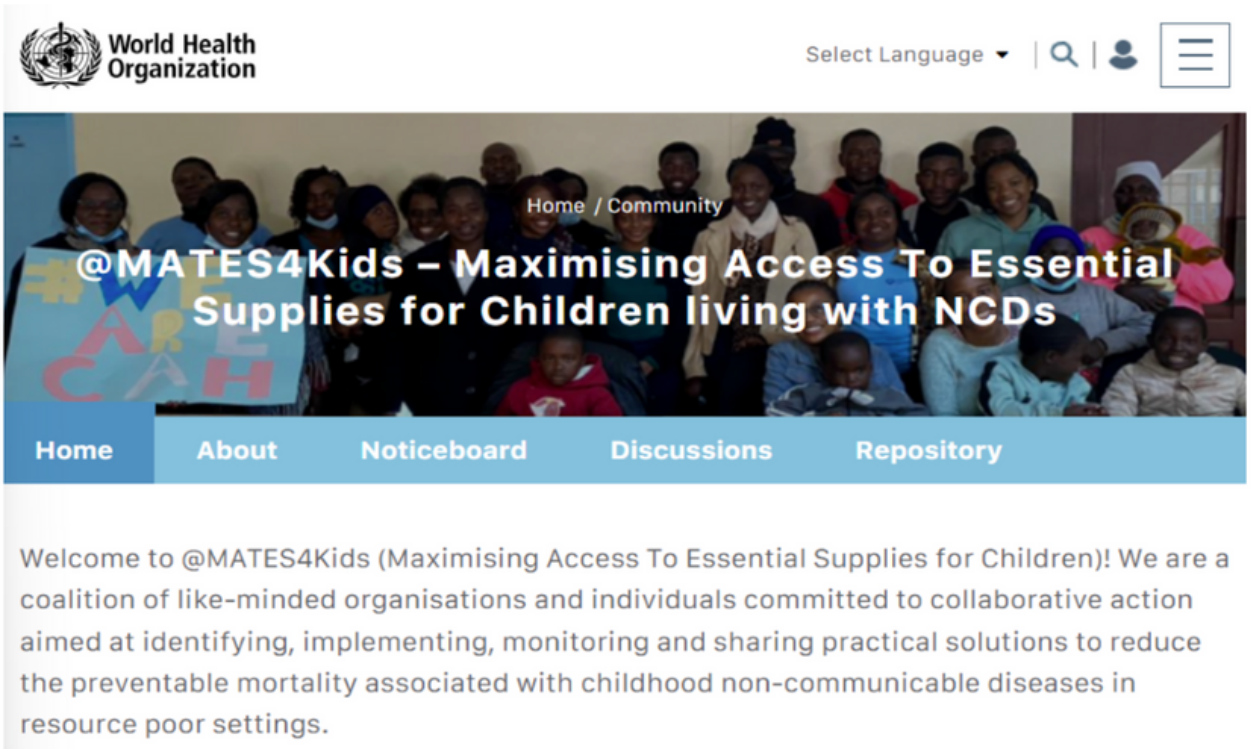


Figure 4: WHO page & proposed framework

The UN #CSocD62 side event was an excellent opportunity to announce the winners of the inaugural CLAN-@MATES4Kids Community Development Grants. Applicants were invited to propose initiatives that would strengthen CAH Communities and/or strengthen national NBS Programs. Winners of the inaugural grants were:

- Dr. Paola Duran – Colombia
- Dr. Navoda Atapattu – Sri Lanka
- Dr. Sumudu Nimali Seneviratne – Sri Lanka

Future @MATES4Kids events will be an opportunity for these champions to share updates on their fantastic collaborative efforts with national CAH Community leaders to drive sustainable change and reduce the preventable mortality associated with CAH in their countries.

Special thanks were expressed to the International Society of Neonatal Screening and LabDiagnostics for awarding the Gerard Loeber Award to Kate Armstrong in 2023 – the fundsallocated with this Award made these inaugural CLAN-@MATES4Kids Grants possible!

Newborn Screening in Indonesia

Elizabeth Page
New Colombo Plan Scholar, Masters of Public Health Student
University of Western Australia

Interview with Minister of Health, Budi Gunadi Sadikin

In preparation for this CSocD62 side event, Eiiabeth Page had the privilege of interviewing the Indonesian Minister for Health, the Hon Budi Gunadi Sadikin. A full recording of the interview is available online, and some key insights are shared below.

Why is NBS a priority for Indonesia?
The Minister of Health spoke on the high infant mortality in Indonesia, specifically 19 deaths per 1000 live births. The target is to reduce this to below 10. The importance of NBS is that it address morbidity and mortality

What is the current status of NBS in Indonesia?
4.8 million babies born each year in Indonesia, accounting for the 5th highest birth rate in the world. As for NBS, the Minister of Health stated the coverage of these babies has drastically increased:

- 2022: 2.3% (1,000 per week) → end of 2023: 65% (60,000 per week) → 2024 Target: 90% (80-85,000 per week)
- In 2024, NBS will include Congenital Hypothyroidism (CH), Congenital Adrenal Hyperplasia (CAH), and G6PD Deficiency

Figure 5: Screenshot of Interview with Indonesian Minister of Health

What level of staffing & resourcing has been required to scale the NBS program to this magnitude?

From 2000-2005, there were two central labs in Bandung (RSHS) and Jakarta (RSCM). This has been extended to 11 hospitals to serve the whole nation. In 2024, Indonesia plans to develop a nation-wide public health lab infrastructure:

- 10,000 Puskesmas (community health centres)
- 540 public health labs in cities
- 34 regional public health labs

How are you making NBS available across such a large country?

Indonesia contains 280 million people spread across 7000 inhabited islands. Thus, revitalising and utilising the Public Health network (Puskesmas) is essential:

- Extending from the central government to district level health facilities
- Responsibility for NBS
- September 2023: national policy mandating NBS provision for health workers to claim delivery rates

What impact has NBS had so far?

NBS is critical for becoming a High-Income country (HIC). The Minister of Health highlighted that now is the window of opportunity for Indonesia to become a HIC.

- Peak demographic bonus
- Indonesia: 2030
- Increase GDP from 5 million rupiah → 15 million rupiah

NBS → a healthy & smart population → increase income → reach HIC status

What is your vision for NBS in Indonesia going forward?

He aimed to reach 90% NBS coverage by the end of 2024, and leave a legacy of three new screening tests (CH, CAH, G6PD). He also aimed to:

Establish an NBS infrastructure

- Increasing the number of labs
- Financing structure
- Training healthcare professionals
- Educating mothers

Improve the quality of NBS

- Sampling (increase positivity rates)
- Follow-up positive tests (reduce rejection rates)
- Treatment access

YICAG Yayasan Kesehatan Anak Global

IKATAN DOKTER ANAK INDONESIA IDAI

KEMENTERIAN KESEHATAN REPUBLIK INDONESIA

NBS Success Story from Indonesia

Prof. Aman B Pulungan

Professor of Pediatrics - Faculty of Medicine Universitas Indonesia, Executive Director International Pediatric Association, NCD Child Governing Council, Project Leader - CDiC Indonesia

SDG Goal 3

Prof Pulungan started with introducing the world's "to-do" list by 2030–the combination of SDGs. He highlighted goal 3 in particular, which is good health and well-being, to ensure healthy lives and promote well-being for all at all ages.

Goal 3 seeks to ensure health and well-being for all, at every stage of life. The Goal addresses all major health priorities, including reproductive, maternal and child health; communicable, non-communicable and environmental diseases; universal health coverage; and access for all to safe, effective, quality and affordable medicines and vaccines. It also calls for more research and development, increased health financing, and strengthened capacity of all countries in health risk reduction and management.

Global NBS

The early identification of inborn disorders through NBS programs is crucial in safeguarding children's well-being and mitigating potential long-term health impacts. Most developed countries have introduced national newborn screening (NBS) programmes to provide early asymptomatic recognition of a defined panel of disorders where early treatment is effective. NBS is also becoming available in many developing regions.

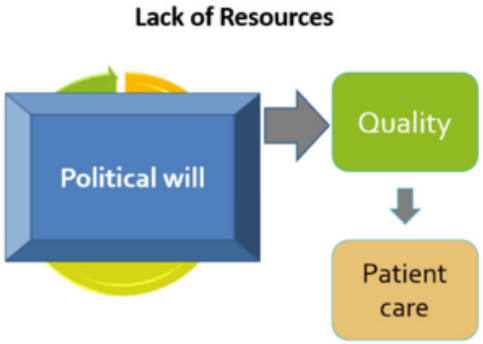


Figure 6: Challenges of NBS in Developing Countries

History & Development of NBS in Indonesia

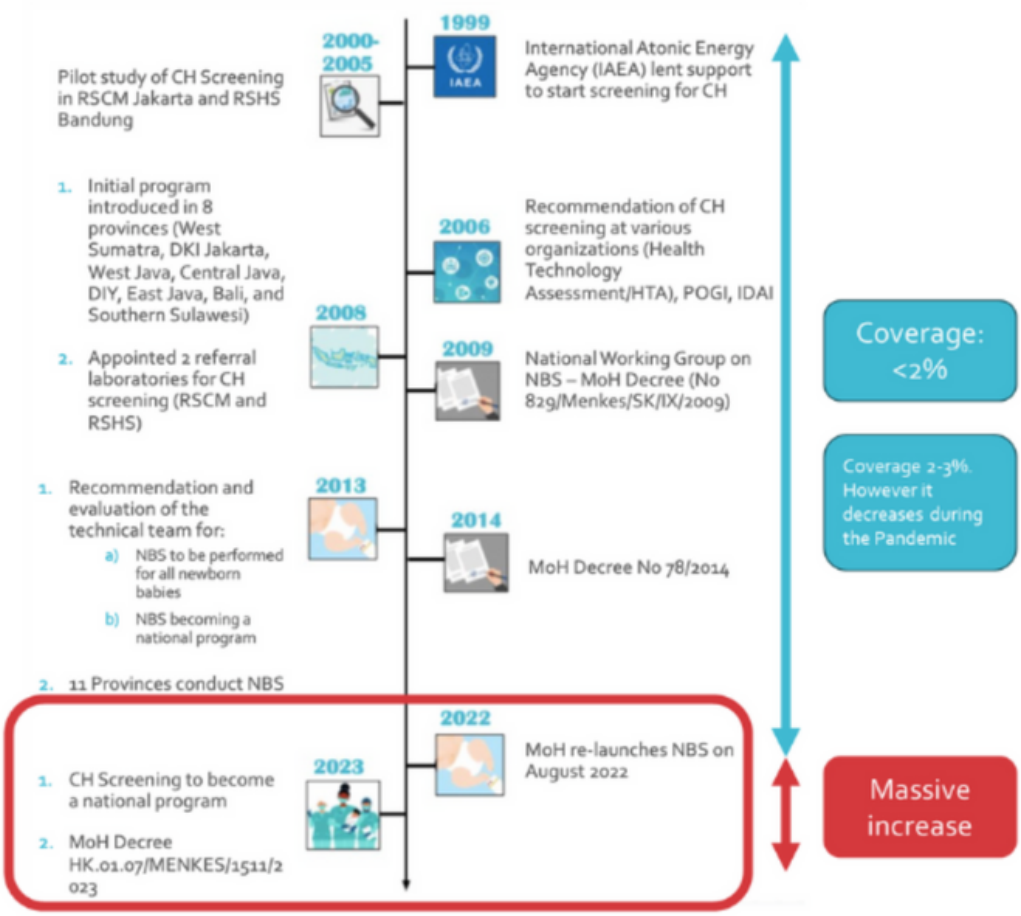


Figure 7: Timeline of NBS Initiatives in Indonesia

Prof Pulungan stated that the 2019 Congenital Hypothyroidism Screening Report for Indonesia only recorded 2.57% of newborns screened for CAH. His recent publication (Preliminary Study of Newborn Screening for Congenital Hypothyroidism and Congenital Adrenal Hyperplasia in Indonesia, 2020) described a multicenter, cross-sectional study in Denpasar (6 hospitals), Banten (8 hospitals), Jakarta (14 hospitals), Semarang (1 hospital), and Yogyakarta (1 hospital). Heel prick blood samples were obtained from 1226 newborns, tested for TSH and 17-OHP. Of these:

- 1 out of 1226 patients was positive for CH screening & patient was recalled & tested & positive for CH & referred to pediatric endocrinologists
- 10 out of 1188 patients were positive for CAH screening & recalled for confirmatory testing but only 3 came & two were positive & referred to pediatric endocrinologists

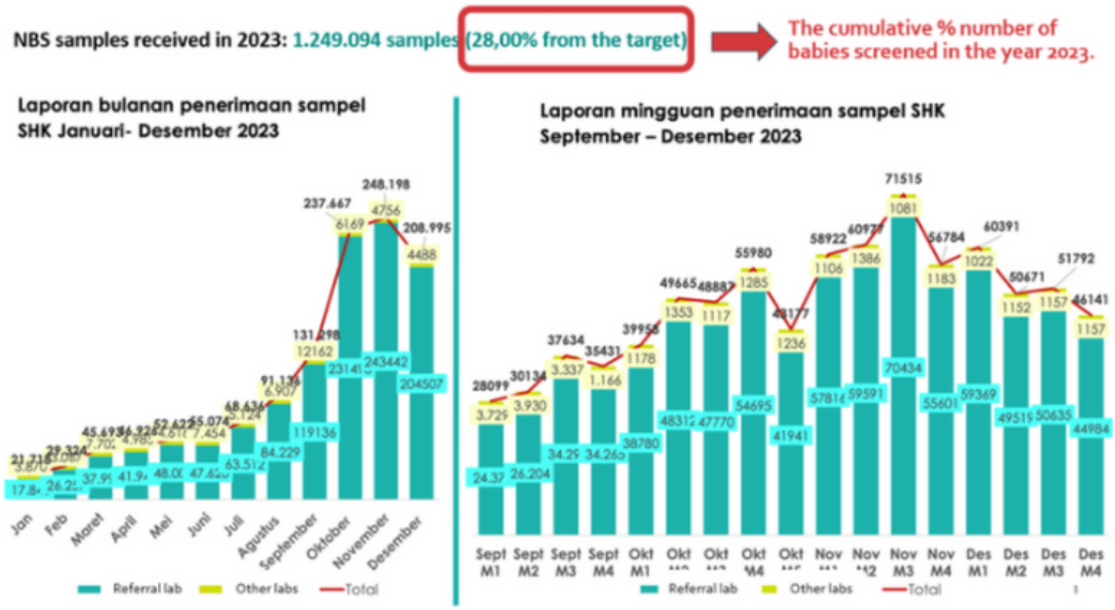


Figure 8: Significant increase in NBS rates by 2023

Lessons Learned

Prof Pulungan highlighted that prioritizing NBS gives an opportunity for every babies to live and grow healthily as well as the significance of commitment and harmonious collaboration between stakeholders and overcoming technical barriers. Such barriers include:

- Increasing number of labs, training health workers
- Indonesia – vast geographic locations
- Integrating NBS in the healthcare system and programs

In addition Prof Pulungan advocated for Increasing awareness for mothers and families to consent for screening. Ultimately, his message was:

“Let’s strive to ensure all newborns are screened”

Neonatal Screening in Mexico

Dr. Raúl Calzada León
Chief of Endocrinology Service - National Institute for Pediatrics, Mexico City

The Beginnings

Dr Calzada introduced the origins of screening. From 1973 to 1977, Dr. Antonio Velázquez carried out the first study on neonatal screening. This included Phenylketonuria, galactosemia, maple syrup urine disease, homocystinuria and tyrosinemia. This project was canceled in 1977, even though it demonstrated its feasibility and effectiveness. However, Dr. Velázquez did not give in to adversity and with the support of the U.N.A.M., he established the Genetics of Nutrition Laboratory in collaboration with the National Institute for Pediatrics in 1986, and the Endocrinology Service began its collaboration. He later reattempted, this time aimed at the detection of congenital hypothyroidism and phenylketonuria.

- In the initial sample, 140,163 children were included and the concentration of TSH was determined using a Spectraplate immuno-enzymatic assay (Tokyo, Japan)
- 78 cases of congenital hypothyroidism were found, which allowed demonstration of a general incidence of 1:1,797

Timeline

Dr Calzada discussed the progress in Mexico made in screening over the late 20th century:

- **1988**: Mexican Official Standard N° 34 was generated, and published in the Official Gazette of the Federation, which made Neonatal Screening mandatory in the country
- **1992**: Three more laboratories in Torreón (North), León (Middle) and Mérida (South), began to operate to cover the entire country
- **1994**: One laboratory in each State of the country
- **1997**: The Mexican Consensus Group on Pediatric Endocrinology demonstrated to the Health authorities several failures in the pre-analytical, analytical and post-analytical phases and proposed viable solutions, which allowed for substantial improvement in the effectiveness of the procedure

Figure 9: Reina Sofia Award in Research (January 24, 2001)

From such work, Dr Calzada highlighted that many lines of research, many publications, and multiple national recognitions have resulted. By 2013, NBS had covered more than 99% of the Mexican population, and the age at which treatment begins had been lowered to 10-15 days of life.

Inborn Errors of Metabolism Dr. Antonio Velázquez Dra. Marcela Vela Dra. Leticia Belmont	**Genetics** Dra. Alessandra Carnevale Dra. Victoria del Castillo	**Imagenology** Dr. Raúl Takenaga Dra. María Antonieta Mora Dra. Sara Solórzano
Psychomotor Stimulation Dra. Carmen Sánchez Dr. Mario Mandujano	**Gastroenterology** Dr. Jaime Ramírez Mayans Dr. Roberto Cervantes	**Cardiology** Dr. Jorge Espino Vela Dr. Alfredo Bobadilla
Statistics Dra. Cristina Sosa	**Endocrinology** Dra. María de la Luz Ruiz Dra. Nelly Altamirano	**Nuclear Medicine** Dra. Estrella Ávila Dra. Rosa María Palma

Figure 10: Current division of departments & leaders

Current Issues

In 2018, equivocal & illogical decisions were made:

- Neonatal Screening cannot be performed if the patient has more than 5 days of life
- Delayed sample processing process
- Lack of coordination between finding an abnormal result and giving the information about it to the family
- Less efficiency and effectiveness
- No information on processes, guidelines, verification of results, mechanisms for reporting results or age at which treatment begins

With conditions such as cystic fibrosis, congenital hypothyroidism, congenital adrenal hyperplasia, galactosemia, glucose 6-phosphate dehydrogenase, and phenylketonuria, Raúl stated that there is still much more progress to be made:

- < 45% coverage
- > 72 days to inform parents
    - Congenital hypothyroidism 7.8 → 87 days of life
    - Congenital adrenal hyperplasia 8.2 → >90 days of life (in 48% the diagnosis is made due to an adrenal crisis)

Use of CHECC Tool in Sri Lankan Setting

Dr. Navoda Atapattu
Consultant Paediatric Endocrinologist - Lady Ridgeway Hospital for Children, Sri Lanka

Sri Lanka

Dr Atapattu began by introducing the situational context of the nation:

- Population – 22 million
- World Bank Ranking – lower-middle income country
- Located in WHO South-East Asian Region (SEAR)
- Child Mortality
    - Under 5 year mortality rate - currently 6-7%
    - Neonatal mortality rate - currently 3-4%

Figure 11: Government expenditure on health 2017-2023

Ensuring Humanitarian Aid reaches those who need it most: Adapting the CHECC Scorecard for Sri Lanka and CAH

Dr Atapattu introduced her experiences adapting the Child health Equity Checklist Count Scorecard (CHECC) for use in Sri Lanka to benefit the CAH Community. The CHECC Scorecard is a tool developed by Dr. Kate Armstrong as part of her DrPH research on Nephrotic Syndrome in Vietnam. The CHECC Scorecard supports rapid identification of children living in the most vulnerable circumstances, and most at risk of failing to survive and thrive the diagnosis of a chronic health condition. Calculating a child's CHECC Score (0-10) involves the rapid review of 10 indicators that reflect key social and cultural determinants of health associated with child health inequities.

Using CHECC Scorecard to decide who receives donated medicines

During the recent financial crisis in Sri Lanka, and in response to requests for assistance to CLAN from health professionals for urgent humanitarian aid, a generous donation of hydrocortisone and fludrocortisone tablets was made possible thanks to financial support from the German CAH Community.

At the time there were an estimated 207 children living with CAH in Sri Lanka, and CLAN was able to facilitate a donation of a year's supply of medicines for 21 children (10%). To ensure the medicines went to those who needed help most, the CHECC Scorecard was used on all children presenting for care. At the time of this event, 107 patients were registered since the commencement of the CHECC tool in Sri Lanka, with each child allocated a score out of ten.

Results

- Majority of children had high CHECC Scores
- More than 89% scored more than 5/10
- 51% of children scored 6/10
- 9/10 was the highest score (5.7% children)
- 13.2% of children scored higher than 8/10

Indicator #1 - Gender distribution
As expected, there were more females than males (atypical genitalia assists with diagnosis where there is no NBS). In Sri Lanka, the gender of the patient is not generally considered to play a major role when families make decisions about seeking and providing medical care.

Indicator #2 - Distance of home from quality health care
In Sri Lanka, families are usually issued with a one month supply of medicines. All children identified through the CHECC as living more than 3 hours (100km) from the clinic were issued a three month supply of medicines to reduce the number of times they had to travel.

Indicator #3 - Ethnicity
The percentage of children from Ethnic Minority groups (40%) was higher than the overall population (25%). Intermarriages are also more common among certain ethnic minorities. At Lady Ridgeway Hospital, specific efforts are routinely in place to support children and families from ethnic minority groups. For instance:

- Access to health professionals from ethnic minority groups
- Access to resources in local language

Tool 7 - CHECC (Child Health Equity Checklist Count) Scorecard

Will a child survive & thrive with a chronic health condition in a resource-poor setting?
Make sure you CHECC risks to survival for EVERY child diagnosed with a chronic health condition so we #LeaveNoChildBehind!

#	Indicator	Criteria	Evidence base / rationale	Score/10
1	Gender	Score 1 if child is female	Some cultures give priority to male children	1*
2	Distance of home from quality health care	Score 1 if child lives more than 3 hours (or 100km) from qualified and trusted health professional	There is decreased access to quality care in remote and rural locations. Travel costs money and time.	1
3	Ethnicity	Score 1 if child is Indigenous or from an Ethnic Minority Group	Indigenous and ethnic minority families experience racism and systemic disadvantage	1
4	Monthly income	Score 1 if out-of-pocket costs of caring for child will be greater than 10% of family's monthly income OR a parent income has been lost as carer	Poverty reduces survival and health outcomes Consider costs of medicine, equipment, health care and travel	1
5	Family structure	Score 1 if child is from a single parent family	Children with chronic conditions from single parent families have poorer health outcomes	1
6	Parent education level	Score 1 if either parent's education is less than Grade 9 level	Health outcomes increase when parental educational levels are higher	1
7	Parental health literacy	Score 1 if parents cannot access culturally appropriate educational resources on child's chronic condition in their own local language	If family do not understand what chronic condition is, nor how to manage it, child health outcomes are likely to be worse	1
8	Parental support and wellbeing	Score 1 if parents have no extended family or local community support to assist with caring for their child OR they report feeling stressed, depressed and unable to cope	Family support (e.g. grandparents, wider family to assist) is associated with better outcomes; social isolation, stigma and parental stress are associated with worse outcomes.	1
9	Child wellbeing	Score 1 if the child is unable to attend school (either now or not expected to attend once older) AND/OR child has more than one chronic condition	Health outcomes are reduced with comorbidities. Children with chronic health conditions should be screened for mental health conditions	1
10	Family support networks	Score 1 point if the family has no access to a support group or network of other people living with the same condition	Support groups can provide people living with chronic conditions with valuable support and information	1
			Total score	10

Child has best chance to thrive

If the CHECC is >3 the child's rights to health and life are at serious risk.
Special action is urgently required if the child is to SURVIVE and THRIVE.
See the CHEAR Toolkit for more information
*Note: Local review of indicators and scores

Survival at risk

372

Indicator #7 - Parental health literacy
At the time of the donation, there were no educational materials on CAH available in local language for families, so all families were marked a point for this. Plans are now underway to develop an educational resource for families.

Indicator #9 - Child wellbeing
All children at the clinic were attending school, so the indicator was marked on the basis of comorbidities only.

Indicator #10 - Family support networks
There were no support groups for CAH in Sri Lanka at the time, so again, all patients were allocated a point for this indicator.

Health Outcomes
- Medicines were distributed to children with the highest CHECC Scores
- No children with CAH died during the economic crisis
- There was no loss to follow up during the economic crisis
- Clinic attendance and compliance improved during the crisis
- Health outcomes improved during the economic crisis (as evidenced by biochemical improvements)

Conclusion & Next Steps
The CHECC Scorecard was a useful tool for identifying children with greatest need. Indicator #2 (Gender) will help track progress towards equity in the absence of newborn screening (aim is for 1:1 ratio)
- Recommended addition of two new indicators for CAH CHECC:
    - Indicator #11 – Does the family have access to emergency injection of hydrocortisone within one hour of home?
    - Indicator #12 – Does the family have an emergency number they can call for advice and support during times of acute illness?
- Proposed next steps include:
    - Information leaflets on acute management of an adrenal crises are now given to patients in their preferred language, however more detailed health information regarding CAH in local language is still being developed
    - Empowering parents and patients to establish a functioning support group

Concluding comments and reflections

CLAN is unwaveringly grateful 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.

It is clear that NBS will have a large role to play in achieving this goal – and the SDGs! NBS is a proven, effective technology, which prevents child morbidity and mortality, and allows for early diagnosis and intervention, ultimately reducing disability and death, and improving the lives of children and families living with NCDs. NBS is especially essential for those burdened by NCDs in resource poor settings as it does not discriminate on the basis of socioeconomic status or gender. Thus, NBS contributes to health equity for all people, regardless of their economic status, which aligns with the focus of the United Nations' Commission for Social Development.

In order to achieve the SDGs by 2030, it is clear we must improve access to essential medicines, scale newborn screening programs, and strengthen NCD communities in resource poor countries. The event's discussions were specifically focused on SDG 3 (Good health and wellbeing), SDG 10 (Reduced inequalities), 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 newborn screening accessible to #EVERYchild and #LeaveNoChildBehind.

Appendix 1 – Full text - CLAN's Written Statement for UN CSocD62

"Caring & Living as Neighbours (CLAN) supports the sixty-second session on the Commission for Social Development and its mission to improve social development to follow up the World Summit for Social Development and twenty-fourth special session of the General Assembly. 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 UN 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% of disability-affected life years and 14.6% of deaths among children and adolescents. In addition, the Centres for Disease Control and Prevention states that noncommunicable diseases account for 41 million deaths each year with about 85% occurring in low- and middle-income countries. With vulnerability of age and socioeconomic factors combined, these children face disadvantaged abilities to live with their conditions.

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 through multisectoral collaborative efforts focused on five pillars considered essential to achieving the highest possible quality of life. CLAN's five pillars focus multisectoral action on:

1. Access to essential medicines and equipment
2. Education, research and advocacy
3. Optimisation of medical management
4. Encouragement of family support groups
5. Reducing financial burdens and promoting financial independence.

Children living with non-communicable diseases in low- and middle-income countries experience inequitable health outcomes due to delayed diagnosis, limited access to affordable medicines, quality healthcare, social services and support. Early diagnosis and treatment of childhood non-communicable diseases has a major impact on improving health outcomes and quality of life. Universal access to Newborn Screening plays a vitally important role in diagnosing many childhood non-communicable diseases at an early stage and can include simple

heel-prick tests (as used for Congenital Adrenal Hyperplasia, Congenital Hypothyroidism, Phenylketonuria and Cystic Fibrosis), hearing tests and pulse oximetry (for Critical Congenital Heart Disease). Whilst available in all high-income countries, Newborn Screening is rarely available in lower income countries. Newborn screening is a vital public health innovation that was first made available in the 1960s. Undertaken in all high-income countries of the world, these 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. For instance, according to the National Institute of Health, in a cohort of infants diagnosed with Congenital Adrenal Hyperplasia, the cost of care was $33,770 per case in unscreened vs $17,726 in screened newborns. Infants screened for the condition were less likely to require medical transport and longer hospital stays, and thus lower hospitalisation costs.

It is unacceptable that newborn screening is not uniformly available to all. Children born with these same non-communicable diseases in low- and middle-income countries are at increased risk of preventable morbidity and mortality. Newborn screening overcomes economic and social inequities. Universal newborn screening programs do not discriminate against girl babies nor babies born in resource poor settings. Newborn screening must be scaled and made available to all – and most particularly to those living in the most vulnerable circumstances. Newborn screening meets World Health Organization screening criteria; it is cost-effective, acceptable, available, and safe. The technology is already developed, and has only to be scaled appropriately to cover more disadvantaged populations.

Scaling newborn screening will enhance efforts to deliver the Sustainable Development Goals in accordance with the 2030 Agenda. Universal implementation of newborn screening supports efforts across multiple SDGs, by reducing inequalities, promoting health and well-being, eradicating poverty, and strengthening infrastructure.

The applicability of rapid scaling is backed by many previous initiatives. For example, the National Institute of Health (NIH) reports that newborn screening in China, a middle-income country, increased newborn screening rates from 2% in 1995 to 97.5% in 2017. With the rapid advances in technology and communication since then, scaling newborn screening globally is attainable, if prioritised.

Universal Health Coverage will be key to scaling access to newborn screening for 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 medicines and equipment required to implement newborn

screening would reap the benefits in terms of reduced developmental delay and disability. With affordable access, families living in the most vulnerable situations would be less likely to be forced into making 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 human development and growth would give children the opportunity to enjoy their basic human 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% 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 social and economic inequities for children living with chronic health conditions in partnership with national and regional civil society organisations and communities, the Commission of Social Development, the WHO, and other relevant United Nations entities. Newborn screening must be seen as a vital component of a holistic, healthsystem strengthening approach. The international community has a tremendous role to play in ensuring children living with non-communicable diseases in resource-poor countries of the world enjoy a quality of life on par with that of their neighbours in wealthier countries. A community development approach to the establishment of screening programs is needed to address poverty and gender inequities in sustainable and holistic ways. Countries must ensure the needs of all children diagnosed with chronic conditions can be met prior to starting screening. This includes affordable access to medicines and equipment; education of families, workforce and the broader community; optimal medical management; strong family support groups; and 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 social or economic inequities. This mission aligns with the standards established by Beijing Platform for Action and takes account of the sixty-second session of the Commission for Social Development priority theme of ‘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.’

CLAN calls upon the Commission for Social Development and other relevant United Nations entities to acknowledge the vital role newborn screening plays in providing early awareness and treatment for young children at risk from the preventable mortality and morbidity too often associated with non-communicable diseases in economically disadvantaged areas. It is essential to increase the span of newborn screening globally; the technology already exists and has been proven reliable and cost-effective. Innovations such as newborn screening and universal health coverage do not discriminate against youth, girls, or lower income families, and should be made available to all. CLAN reaffirms its commitment to eliminate social inequity and eradication of poverty in accordance with the Commission for Social Development and the twenty-fourth special session of the General Assembly. We believe children living with noncommunicable diseases in low- and middle-income countries deserve equal rights to life and prosperity, and thus recognise the indispensable need for social justice and development in order to accelerate the UN Sustainable Development Goals."

Appendix 2 - Full text - CLAN's Oral Statement to #CSocD62

My name is Nicole Pasterczyk and I am a Lehigh University student and a UN Youth Representative for the Australian NGO CLAN and the @MATES4Kids movement. I am also the sister of a sibling living with a rare non-communicable disease, phenylketonuria (PKU), diagnosed by newborn screening (NBS).

A non-communicable disease, or NCD, is a long term health condition that does not spread from person-to-person. Examples include Type 1 diabetes, cancer, asthma, congenital hypothyroidism, PKU, cystic fibrosis and congenital adrenal hyperplasia.

It is estimated that 1 in 4 children live with an NCD. The CDC notes NCDs account for 41 million deaths each year with about 85% in low/middle-income countries. These inequities can be attributed to delayed diagnosis and limited access to medicines, healthcare and social services.

Access to NBS plays an important role in diagnosing many childhood NCDs so that treatment can be started before adverse effects develop. NBS Programs are universally available in high-income countries, including heel-prick blood tests, hearing tests and pulse oximetry checks.

NBS can overcome economic/social inequities as it does not discriminate against babies on the basis of gender, ethnicity or economic status when universally available. NBS meets WHO criteria: it is cost-effective, acceptable, available, and safe.

Rapid scaling of NBS is possible. For instance, the Indonesian Minister of Health has committed to scaling NBS to 90% coverage by the end of 2024 - efforts are so far on track, with this upper-middle income country already scaling newborn screening coverage from just 2.3% of newborns in 2022 to 65% by the end of 2023. These are remarkable achievements, given Indonesia is a vast archipelago, with the 5th highest birth rate in the world (4.8 million babies annually).

Cost benefit analyses show that administrations that cover NBS costs reap benefits in reduced developmental delay/disability. For equitable scaling of NBS, Universal Health Coverage is essential. Families living in vulnerable situations are less likely to be forced into making life-and-death decisions about how to spend limited resources when screening and treatment are affordably available.

Globally, 40 million babies are born annually, yet only ⅓ receive screening. It is unacceptable that NBS is not uniformly available.

My question is: how to we prepare for the Summit of the Future 2024, the UN HLM on Noncommunicable Diseases in 2025, and lead up to the SDGs in 2030, to scale universal coverage of NBS so that we #LeaveNoChildBehind?