



Official Event Report

6-17 March 2023 INNOVATION AND TECHNOLOGICAL CHANGE
EDUCATION IN THE DIGITAL AGE
COMMISSION ON THE STATUS OF WOMEN Progress toward gender equality

Newborn Screening:

Responding to the urgent need to leverage existing technology for gender equality



67th Session of
UN Women's Commission on the Status of Women
#CSW67 for NGOs
6 March 2023

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, and our team of young people who coordinated and chaired this event: United Nations Youth Representatives Nicole Pasterczyk and Sofia Rousseau from Lehigh University; and Youth Advisors Sienna Gates and Grace Strik.

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:

- Asia Pacific Paediatric Endocrine Society (APPES)
- CAH International
- CARES Foundation
- Indonesian Paediatric Society
- International Paediatric Association
- Lehigh University
- Ministry of Health – Republic of Indonesia
- NCDChild

Videos from the event are available on [CLAN's YouTube account](#).

History of Lehigh University and CLAN

This event occurred in partnership with the Lehigh University United Nations Youth Representative Program, which began in 2008. The Program pairs high-achieving Lehigh University students with UN accredited NGOs, allowing youth to have a voice in global matters. At the time of the event, there was a cohort of 22 Youth Representatives serving as the voices of NGOs at the UN. CLAN is one of nine represented NGOs and has been proud to partner with Lehigh since 2015.



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List of Abbreviations

Abbreviation	Full Text
CAH	Congenital Adrenal Hyperplasia
CLAN	Caring & Living As Neighbours
IPA	International Paediatrics Association
MATES4Kids	Maximising Access to Essential Supplies for Kids
NBS	Newborn Screening
NCD	Non-Communicable Disease
NGO	Non-Governmental Organisation
SDG	Sustainable Development Goal
UN	United Nations

We welcome you to watch the event [here!](#)

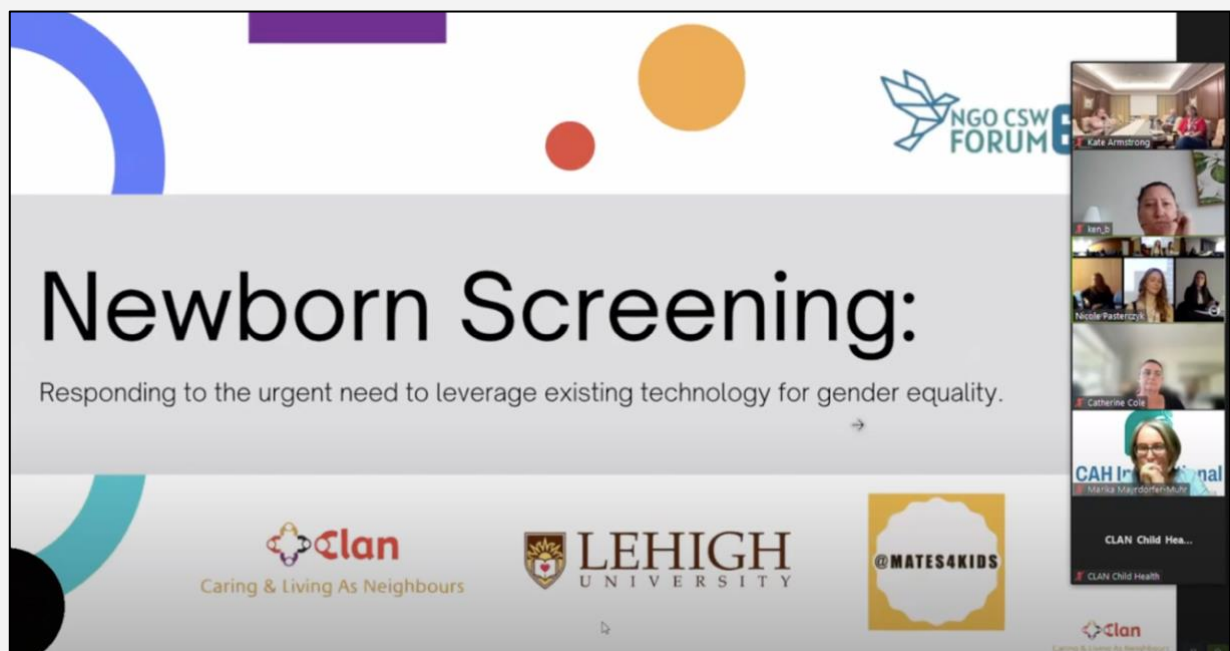


Figure 1 - Screenshot from the hybrid parallel event hosted by CLAN in partnership with @MATES4Kids and Lehigh University at #CSW67 in New York on 6 March 2023.

Executive Summary

CLAN (Caring & Living as Neighbours) was proud to engage in events relating to the 67th Session of the UN Women's Commission on the Status of Women (CSW) in 2023.

The CSW67 Priority Theme was '**Innovation and technological change and education in the digital age, for achieving gender equality and the empowerment of all women and girls**'. The Review Theme was '**Challenges and opportunities in achieving gender equality and the empowerment of rural women and girls**'.

CLAN's goal in engaging in CSW67 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.

CLAN supported @MATES4Kids participation in CSW67 through **three key activities**:

- 1) Submission of a written statement
- 2) Hosting a hybrid event at the Forum for Non-Government Organisations (NGOs)
- 3) Delivery of an oral statement by our UN Youth Representative.

This report provides details on all three of these activities.

The **key objectives** of @MATES4Kids participating in CSW67 were to:

- 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
- Identify practical solutions, successes and achievements in the fields of NBS and childhood NCD prevention and management in resource poor settings
- Provide insights into the perspectives and lived experiences of communities of children and families living with childhood NCDs, as well as their recommendations for change.

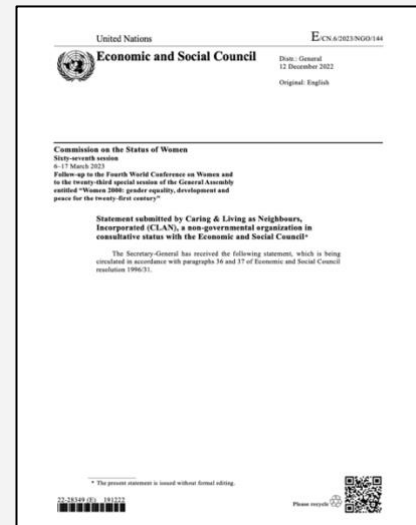
The **key recommendations** from @MATES4Kids emerging from the activities were:

- Advocate for inclusion of NBS within the Universal Health Coverage and Non-Communicable Disease declarations at the 2023 and 2025 UN High Level Meetings.
- Raise awareness of the rights of #EVERYchild living with NCDs to health and life, and the violations that occur as a result of inequitable access to universal NBS.
- Raise awareness of the economic and social benefits of NBS
- Showcase and promote healthy public policy and critical action driving efforts to achieve universal coverage of NBS
- Scale efforts to improve affordable access to essential medicines and equipment for children living with NCDs in resource poor settings
- Scale childhood NCD community development initiatives so #EVERYchild is supported to achieve their full potential following diagnosis.

@MATES4Kids #CSW67 Activities in Focus

Activity 1 – Submission of a Written Statement

CLAN was proud to facilitate submission of a 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 online, and provided in entirety in this report.



Statement

Caring & Living as Neighbours (CLAN) supports the sixty-seventh session on 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. Caring & Living as Neighbours would like to acknowledge the Wallumedegal peoples of the Eora Nation, the Traditional Owners of the land on which we are headquartered. Caring & Living as Neighbours also acknowledges the Lenape people, on which the United Nations is headquartered in New York City, and we pay our respects to Elders past, present, and emerging.

Caring & Living as Neighbours is an Australian non-governmental organization (NGO) founded in 2004 with the mission to maximize the quality of life for children living with Non-Communicable Diseases and other chronic health conditions in poor resource settings. Caring & Living as Neighbours operates under a rights-based strategic framework for action that promotes a community development approach to redressing inequities through multisectoral collaborative efforts focused on five pillars considered essential to achieving the highest possible quality of life. The five pillars focus 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. Actions to reduce financial burdens and promote financial independence.

The World Health Organization (WHO) acknowledges health innovations as new or improved solutions with the transformative ability to accelerate positive health impacts. Innovation is particularly essential for organisations that focus on non-communicable diseases, particularly for communities living in disadvantaged circumstances, as it offers the hope of new life-saving medications, treatments, and awareness to improve life outcomes for those most affected.

Caring & Living as Neighbours is proud to serve as Secretariat for MATES4Kids. MATES4Kids is an international movement committed to collaborative action aimed at identifying, implementing and monitoring practical solutions and innovations to improve access to essential medicines for children living with chronic health conditions. Newborn screening is one such innovative public health solution.

Newborn screening continues to be a public health innovation long after its introduction in the 1960s. Quick, affordable and simple heel-prick blood tests from newborn babies are now combined with other low-cost initiatives (such as hearing and pulse oximetry screening tests on newborns) undertaken in all high-income countries of the world, and have the potential to diagnose conditions requiring urgent (yet affordable) treatment to prevent profound developmental delay, disability and even death. Phenylketonuria, Congenital Hypothyroidism, Congenital Adrenal Hyperplasia and Cystic Fibrosis are amongst the many congenital conditions that can now be diagnosed and treated early in order to redress preventable childhood mortality and morbidity.

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. 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 non-communicable diseases account for 41 million deaths each year with about 85% occurring in middle- and low-income countries. With vulnerability of age and socioeconomic factors combined, these children face disadvantaged abilities to live with their conditions.

Of all children living with chronic conditions, girls are at increased risks from preventable morbidity and mortality associated with non-communicable diseases. In low- and middle-income countries, women have less access to care, and when they do, they often receive less aggressive treatments due to a lack of gender-specific guidelines on non-communicable diseases, therefore increasing their risk of complications and denial of their basic human rights to life and health.

Newborn screening overcomes gender inequities (universal newborn screening programs do not discriminate against girl babies) and has the potential to cut through the social and cultural determinants of health. When available equally to every newborn child, newborn screening can overcome gender inequities, but it 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, and is low-cost, effective, acceptable, available, and safe. The technology is already developed and has only to be scaled appropriately to cover more disadvantaged populations.

Universal Health Coverage will be key to scaling newborn screening to all children around the world. Cost benefit analyses have clearly demonstrated the value of newborn screening, and administration 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 in vulnerable situations would be less likely to be forced into making decisions about how to spend limited resources. Optimal treatment of childhood non-communicable diseases during the “golden years” would give children the opportunity to enjoy their rights to life and health and reach their full potential.

Caring & Living as Neighbours and the MATES4Kids movement is 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 World Health Organisation, and other relevant United Nations entities. The international community has a tremendous role to play in ensuring children living with non-communicable diseases in resource-poor countries of the world will enjoy a quality of life on par with that of their neighbours in wealthier countries. Caring & Living as Neighbours emphasizes 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 preventable causes. This mission aligns with the standards established by Beijing Platform for Action and takes account of the sixty-seventh session of the Commission on the Status of Women’s priority theme of “innovation and technological change, and education in the digital age for achieving gender equality and the empowerment of all women and girls.” In this context, Caring & Living as Neighbours would like to especially underscore the vital role newborn screening technology has to play in providing equal, accessible treatment for women and girls.

Caring & Living as Neighbours calls upon the Commission on the Status of Women, UN-Women, and other relevant United Nations entities to acknowledge the vital role newborn screening plays in providing early awareness and treatment for women and girls suffering from noncommunicable diseases. It is essential to increase the span of newborn screening globally; the technology already exists and has been proven reliable and cost effective. If it were to be scaled globally as a matter of urgency, there would be significantly improved health outcomes for those affected by congenital noncommunicable diseases.

Caring & Living as Neighbours calls upon the Commission on the Status of Women, UN-Women, and other relevant United Nations entities to recognize the vast potential of newborn screening, Universal Health Coverage, and technological change and innovation in redressing inequities and protecting the rights of children living with non-communicable conditions in resource poor settings. Innovations such as newborn screening and universal health coverage do not discriminate against women and girls and should be made available to all.

Caring & Living as Neighbours 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.

Activity 2 – CLAN’s parallel event at #CSW67 NGO Forum

CLAN was proud to host a hybrid Parallel Event to the Commission on the Status of Women 67th Session (CSW67) NGO Event at the United Nations Church Centre, New York, United States, on 6th of March 2023, and partner with global changemakers to discuss the role of Newborn Screening (NBS) in driving gender equity in the contemporary technological age.

CLAN’s Parallel NGO Event was entitled ‘**Newborn Screening: Responding to the Urgent Need to Leverage Existing Technology for Gender Equality**’. The event brought together experts from around the world to highlight the importance of scaling Newborn Screening to achieve the Sustainable Developments Goals (SDGs), and reduce gender inequalities affecting young girls living with non-communicable diseases (NCDs) in resource poor settings. Speakers from Australia, Austria, Indonesia, New Zealand, Pakistan, the United States of America and Zimbabwe participated, representing a broad range of NGOs and organisations working in the field of NBS and caring for children living with NCDs.

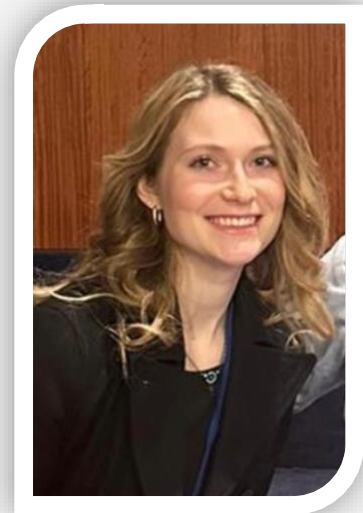
Agenda

Topic/Title	Speaker	Content Overview
PART 1 - INTRODUCTION		
Welcome	Ms Nicole Pasterczyk	<ul style="list-style-type: none"> • Acknowledgement of Country • Housekeeping • Introductions • Overview of NBS
Success Story	CARES Video	<ul style="list-style-type: none"> • Mother of child with CAH shares lived experience with diagnosis through NBS
Introduction to CLAN	Ms Sofia Rousseau	<ul style="list-style-type: none"> • CLANs mission and vision • CLANs Strategic Framework for Action and 5 Pillars • History of Lehigh and CLAN partnership
Introduction to @MATES4Kids	Dr Kate Armstrong	<ul style="list-style-type: none"> • M4Ks mission and vision • Relationship to NBS • M4K timeline to reduce preventability mortality by 30% by 2030
PART 2 - KEYNOTE SPEAKERS		
A bold vision for Indonesia - expanding NBS across the Archipelago	Mr Budi. Gunadi Sadikin Minister for Health, Indonesia	<ul style="list-style-type: none"> • Highlights the need to scale NBS, due to the burden of disease arising from screened conditions. • Demonstrates the positive outcomes associated with NBS and scaling of the same.
How will NBS help	Dr Aman Pulungan	<ul style="list-style-type: none"> • Discusses the distribution of CAH in

reduce mortality and achieve the SDGs?		<p>Indonesia.</p> <ul style="list-style-type: none"> • Contrasts coverage of NBS in Europe and Asia. • Reflects on results of Indonesian cross-sectional multi-section study of NBS. • Explores need for scaling of NBS, including the outcomes of inaccessibility of NBS. • Highlights obstacles to the scaling of NBS in specific regions.
Why is NBS so important for girls?	Ms Fatima Idaayen	<ul style="list-style-type: none"> • Reflects on the inequitable burdens of congenital disorders upon girls, and female caregivers. • Shares results of interviews with 40 families in Indonesia and their concerns arising from late diagnosis. • Highlights the importance of NBS to achieve gender equality.
Is NBS cost-effective?	Ms Emma Santini	<ul style="list-style-type: none"> • Highlights the need for economic analyses of NBS, and how such outcomes are used in policy-making. • Discusses recent economic analyses conducted.
PART 3 - PANEL DISCUSSION		
Understanding NBS around the world and mapping a way forward	Marika Dianne Webster Dina Matos	<ul style="list-style-type: none"> • Contrasts global coverage and availability of NBS. • Highlights inequitable burdens faced by those in resource-poor settings. • Discusses technological advancements and their positive outcomes in light of NBS. • Reflect on psycho-social implications of early intervention and diagnosis. • Demonstrates further work to be conducted in ensuring universal access to NBS.
PART 4 - CONCLUSION		
Closing remarks	Ms Grace Strik	<ul style="list-style-type: none"> • Reflects on key themes arising from the event and speaker presentations. • Encourages audiences to take positive action in the fight for universal access to NBS.
Formalities	Ms Sienna Gates	<ul style="list-style-type: none"> • Directs the audience to further resources regarding contents of the event. • Housekeeping.

Introduction

Speaker: Ms Nikki Pasterczyk
United Nations Youth Representative for CLAN

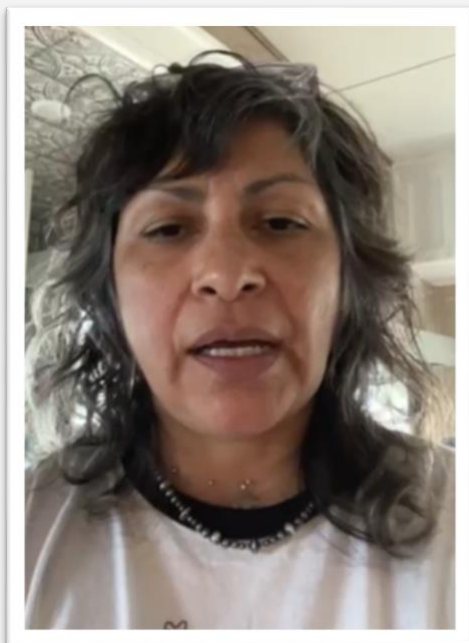


What is Newborn Screening?

NBS is a vitally important public health initiative. NBS facilitates the early diagnosis and management of a range of genetic, metabolic, endocrine, and other long-term health conditions (NCDs) that would otherwise result in disability and death if they went undetected.

NBS was first started in the United States by Dr Robert Guthrie in the 1960s, where heel-prick blood tests from newborn babies were used to diagnose Phenylketonuria (PKU) at an early stage in life, allowing the start of effective treatments that protected babies with PKU from developmental delay and disability. NBS heel-prick panels have since expanded, and can now diagnose a broad range of conditions, including Congenital Hypothyroidism (CH) and Congenital Adrenal Hyperplasia (CAH). In addition, early hearing tests and pulse oximetry testing can detect hearing and heart problems at an early stage, allowing effective treatments that maximise a child's opportunities to reach their full potential in life.

NBS Programs are now almost universally available in all high-income countries around the world. Regrettably however, NBS is largely unavailable in almost all low-income countries of the world. There is enormous preventable morbidity and mortality that results from this inequity.



Newborn Screening saves lives!

In high income countries around the world NBS programs are saving the lives of children living with CAH on a daily basis. [Kristie's story](#) (Figure 2) was a powerful reminder of the impact NBS can have on the lives of babies and their families!

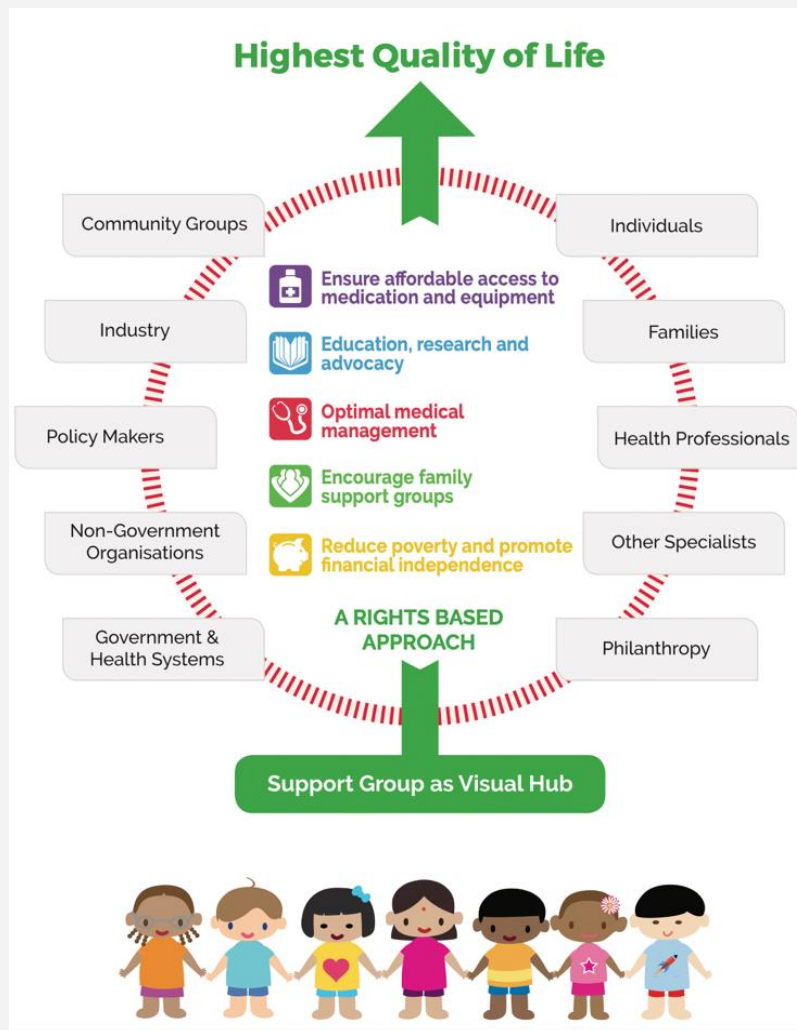
Figure 2 – Kristie sharing her story.

CLAN's Strategic Framework for Action & 5 Pillars

Speaker: Ms Sofia Rousseau
United Nations Youth Representative for CLAN

CLAN is an Australian non-governmental organisation (NGO) founded in 2004 with a vision that all children living with chronic health conditions in resource poor settings of the world would enjoy a quality of life on par with that of their neighbours' children in wealthier countries.

CLAN's work began in Vietnam, where consultation with the local CAH Community led to development of CLAN's Strategic Framework for Action and five pillars (**Figure 3**).



CLAN's Strategic Framework is underpinned by a rights-based, community development approach, and facilitates comprehensive, collaborative action by a broad range of stakeholders to effect long-term sustainable change.

Figure 3 - CLAN's Strategic Framework for Action

The @MATES4Kids Movement

Speaker: Dr Kate Armstrong

- **President, CLAN (Caring & Living As Neighbours)**
- **Co-Founder, @MATES4Kids (Maximising Access To Essential Supplies 4 Kids)**
- **Public Health Physician (B Med, DCH, MPH, FAFPHM, DrPh); Associate Professor, Torrens University**



@MATES4Kids (Maximising Access to Essential Supplies for Kids) is a coalition of like-minded organisations and individuals committed to collaborative action aimed at reducing the preventable mortality associated with CAH by 30% by 2030 and contribute to efforts to achieving the SDGs (notably SDGs 3.2.1, 3.2.2 and 3.4).

Achieving the SDGs: Scaling NBS to reduce mortality

The 17 SDGs are described by UN Women as ‘the blueprint to achieving a better and more sustainable future for all.

The CSW67 forum specifically focussed on SDG 5 (Gender Equality), SDG 10 (Reduced Inequalities), and SDG 17 (Partnerships for the goals). CLAN’s Parallel Event highlighted the intersection of SDGs 5, 10 and 17 with SDG 3 (Good health and wellbeing). In particular, reducing the preventable mortality associated with CAH will help achieve the following SDGs:

- SDG 3.2.1 – Reduce under-five mortality rate (per 1000 live births)
- SDG 3.2.2 – Reduce neonatal mortality rate (0 to 27 days) per 1000 live births)
- SDG 3.4 – Reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being.

NBS promotes gender equity

Scaling access to NBS will help redress existing inequities associated with many childhood NCDs. In some countries, girl babies and children with chronic health conditions are at increased risk of preventable mortality. Moreover, the burden of caring for children living with disability and chronic health conditions most usually falls to mothers. Improving universal access to NBS programs will contribute to efforts to redress gender inequities.

A Roadmap to 2030

@MATES4Kids proposes to reduce mortality associated with CAH through:

- 1) Improving access to essential medicines and equipment
- 2) Strengthening CAH Communities and
- 3) Scaling access to NBS.

@MATES4Kids is establishing a Community of Practice to facilitate collaborative action to identify, implement, monitor and share practical solutions with and for the international CAH Community as we approach 2030.

The @MATES4Kids movement has prepared a Briefing Paper (**Figure 4**) outlining our ambitious goals and proposed activities to help achieve the SDGs (available online [here](#)).

Through collaborative action, leverage of major international and multilateral events, and a strategic regional and phased approach, we believe it will be possible to make a meaningful difference for people living with CAH in resource poor settings around the world.

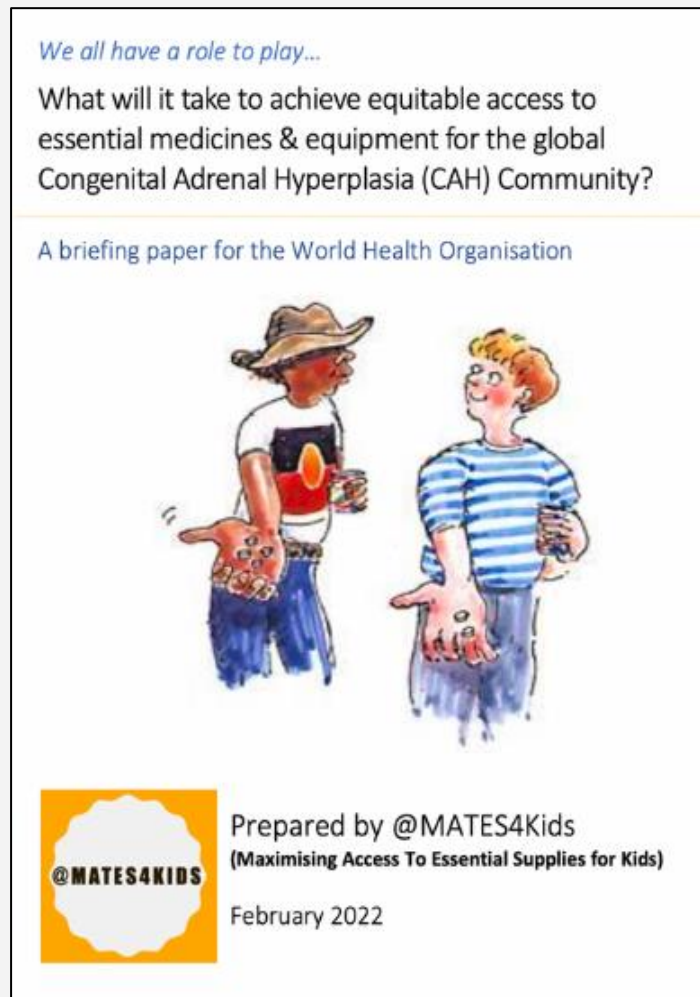


Figure 4 - @MATES4Kids Briefing Paper

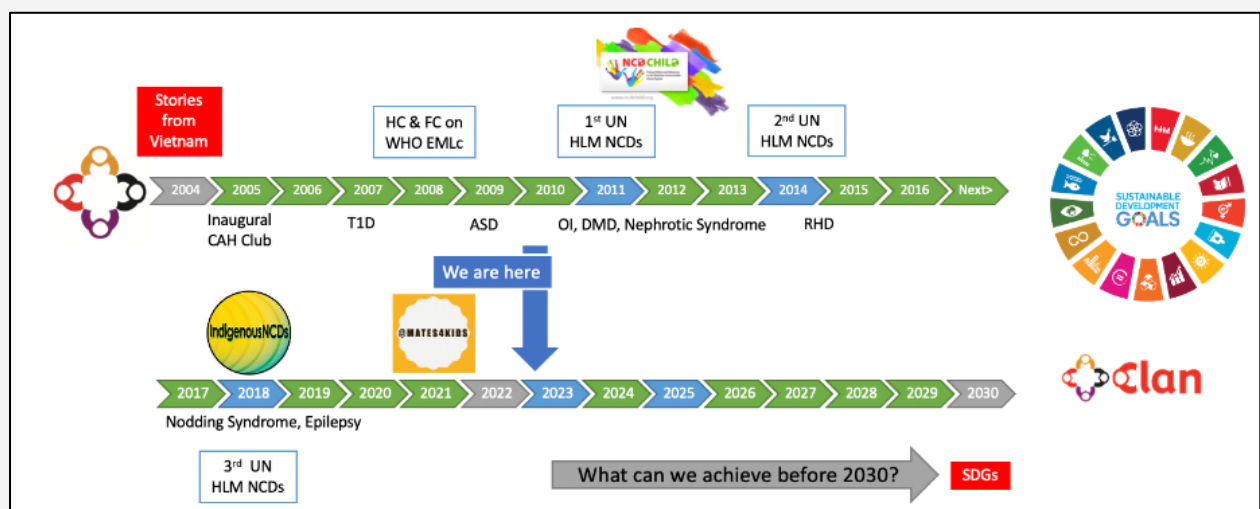


Figure 5 - The @MATES4Kids Roadmap to 2030

Indonesia: A Case Study

Address from the Honorable Minister

Speaker: Mr Budi Gunadi Sadikin, Minister for Health, Indonesia



The Honourable Minister for Health Mr Budi Sadikin shared a video contribution ([watch here](#)) with participants, and spoke on the bold vision Indonesia has for expanding NBS across the Archipelago region, and achieving gender equality.

The work to scale NBS that is underway in Indonesia is occurring in recognition of the vital need for universal access to this technology. The Hon Minister acknowledged an estimated 8 million, or 6% of newborns worldwide are suffering from a congenital disorder, and globally these conditions contribute to the top five burdens of disease. In Indonesia congenital conditions are a leading burden of disease in babies and toddlers, and an estimated 48,000 newborns are at risk of developing congenital heart disease every year. Further, for every 12,000 babies screened, 1 suffered from congenital hypothyroidism (CH).

Newborn screening provides opportunity for the early detection and treatment of medical conditions, particularly in cases where newborns have no family history of the disorders screened for, and show no early signs or symptoms. Early diagnosis leads to early intervention to contribute to longevity, and long-term health and wellbeing. Heel-prick blood tests for newborn babies can aid in preventing developmental delay, disability, and death. The Indonesian health system is currently undergoing transformation to ensure every newborn has access to heel-prick blood tests and screening tests to reduce preventable morbidity and mortality. This transformation is being undertaken across primary and secondary healthcare systems.

The Honourable Mr Sadikin closed by encouraging reflection upon innovation and support which can be provided to scale availability of NBS technologies to achieve gender equality.

***"It is time for all of us to work together to build a better future for women and children."
The Honourable Mr Budi Gunadi Sadikin.***

Speaker: Dr Aman Pulungan

- *Professor of Pediatrics, Paediatric Consultant, MD, PhD, FAAP, FRCPI*
- *Executive Director - International Pediatric Association (IPA)*
- *Senior Consultant, Pediatric Endocrinology*
- *Faculty of Medicine, University of Indonesia*
- *Governing Council Member - NCD Child*
- *Past President of the Asia Pacific Pediatric Association, Indonesian Pediatric Society, Asia Pacific Pediatric Endocrine Society (APPES)*
- *Health Advisory Board Member - Australia-Indonesia Centre*
- *Editorial board of International Journal of Pediatric Endocrinology, The Annals of Pediatric Endocrinology & Metabolism, and Human Biology and Public Health*



Dr Pulungan provided detailed insights from a clinical perspective on the need for NBS in Indonesia, as well as highlighting its challenges and benefits.

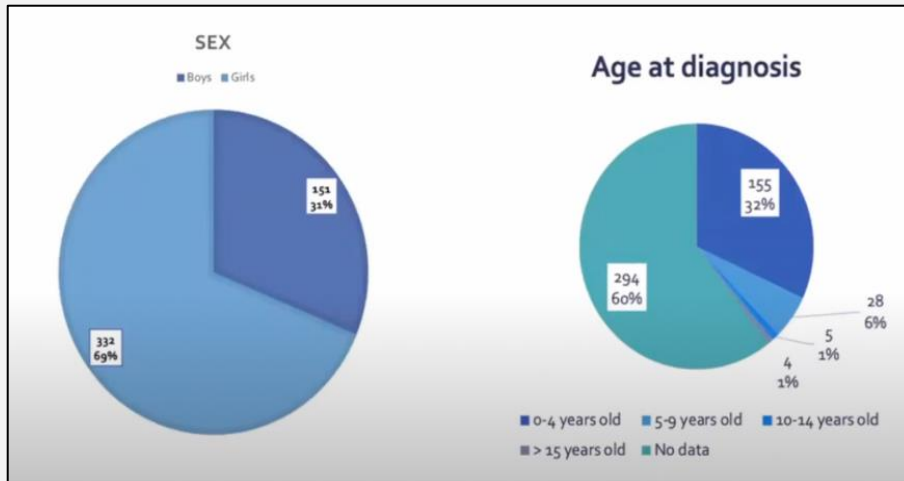
Currently only about 2% of newborn babies across Indonesia are routinely screened at birth, but efforts are underway to increase screening rates to 50%.

The low rates of screening have an impact on child mortality. This was powerfully demonstrated using CAH as an example. The current rates of incidence of CAH around the world were shared, and include:

- | | |
|--------------------------|--------------------------|
| ● Philippines 1 : 5,9333 | ● Belgium 1 : 25,000 |
| ● Japan 1 : 220,000 | ● Switzerland 1 : 12,733 |
| ● Taiwan 1: 14,822 | ● France: 1 : 11,661 |
| ● Thailand 1: 58,563 | ● Italy 1 : 11,666 |
| ● Singapore 1 : 22,222 | ● Sweden 1 : 11,612 |
| ● India 1 : 6,813 | ● Netherlands 1 : 11,778 |

Whilst the incidence of CAH in Indonesia is unknown, the prevalence and demographic profile were shared (see **Figure 6**).

Based on incidence rates internationally, it is reasonable to assume there should be around 20,000 people living with CAH in Indonesia currently. Instead, there are currently just under 500 children known to be living with CAH in Indonesia.



**Figure 6 -
Distribution of CAH
in Indonesia (n=486)**

It is vitally important that efforts to scale NBS in Indonesia continue. If NBS is not scaled, babies living with CAH and other congenital conditions in Indonesia cannot be identified and treated early. Instead these babies will not just experience enormous preventable morbidity and mortality, but also increase the burden on society, with increased hospitalisations and healthcare costs, increased disability and developmental delay, and of course, increased mortality.

A study undertaken by Professor Pulungun and colleagues entitled 'Preliminary Study of Newborn Screening for Congenital Hyperthyroidism and Congenital Adrenal Hyperplasia in Indonesia', included a cross-sectional, multi-center study across the entirety of Indonesia, including over 30 hospitals, with 1226 newborns tested for thyroid-stimulating hormones (TSH), and 17-OHP Progesterone, which facilitates the diagnosis of CAH. The study identified a range of factors that present barriers to NBS, such as reluctance of parents to engage, and low commitment of hospitals to contact and trace babies diagnosed through NBS. As a result, improvements in awareness and partnership will be of utmost importance moving forward.

Other obstacles to scaling NBS in countries such as Indonesia include: the very large populations (there are 4 million babies born each year in Indonesia!); high rates of home deliveries; lack of laboratories and trained personnel; early discharge of women from hospital due to high birth rates and demand; and the unaffordable cost of treatment. Further, many families in Indonesia face financial burdens once a child is diagnosed with a chronic condition such as CAH, largely due to the lack of national health insurance. Moving forward, a national system to develop a NBS task force is required, including economic analyses, and increased awareness of civil society and healthcare providers is required to achieve aspirations for universal access to NBS. Scaling of NBS will require political will, healthcare provider awareness, infrastructural support and parent and community awareness.

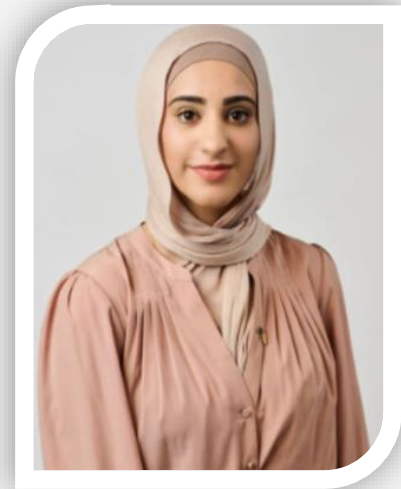
"It doesn't matter when we start. It doesn't matter where we start. All that matters is that we start."
Professor Aman Pulungan quoting Simon Sinek.

The Intersection: NBS and Gender Equity

Speaker: Ms Fatima Idaayen

- *Newborn Screening Community Development Officer - Caring and Living as Neighbours (CLAN)*
- *NBS intern - The International Pediatric Association (IPA)*

Intern - Directorate of Nutrition and Mother and Child Health, Ministry of Health of the Republic of Indonesia



Ms Fatima Idaayen spoke about the importance of Newborn Screening for girls, particularly in the context of screening for CAH. NBS is a vital public-health measure which can ensure early diagnosis and subsequent intervention prior to symptoms presenting, preventing serious impacts on quality of life in the long-term. For NCDs such as CAH, early intervention is vital, as the condition can be effectively treated and managed with medication. Girls living with CAH are affected differently to boys. Moreover, without treatment, girls are at a higher risk of negative psychological impacts of CAH due to the impact of excess androgens. High quality health care and management of CAH, beginning with early diagnosis and intervention through NBS, and enhanced by educational resources that enable patients and families to self-manage CAH is very effective however, and in the long term, promotes the highest quality of life possible.

Ms Idaayen interviewed 40 families in Indonesia who live with CAH, to obtain insights into their experiences with NBS. Many families indicated they could not afford the relevant medications, resulting in rationing or foregoing the required tablets, and high costs arising from transportation. Families wanted greater access to publicly available information on CAH, and support with education, self-management and advocacy. When comparing families who experienced early-diagnosis of CAH through NBS to those who were diagnosed later, it was clear that early intervention resulted in better physical and psychological development. Girls with CAH face specific challenges related to gender identity, which can be exacerbated by late diagnosis, puberty, stress, friendships, cultural norms and stigma. Many mothers of children with CAH also faced disproportionate stressors and mental health issues. In attaining treatment, many families indicated they feared scrutinisation. Looking to the future, concerns with intimacy, partner acceptance and reproduction for girls living with CAH were high.

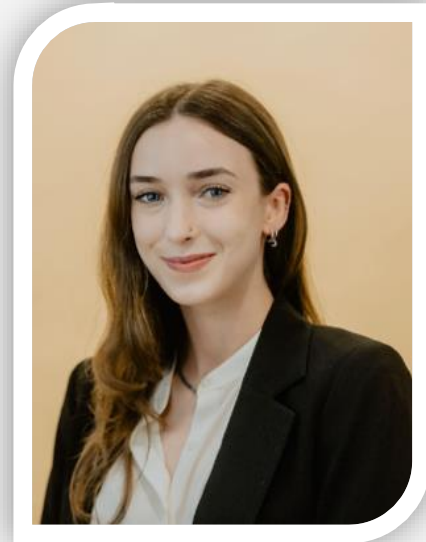
The need to leverage NBS is crucial, as it offers the opportunity to prevent serious and preventable side effects of many congenital disorders. Due to the inequitable impact on girls and mothers, and the exacerbated discrimination experienced without early intervention, the need to ensure universal, and thus equitable, access to NBS is clear. Nations such as Indonesia are making great progress and continue to enhance coverage whilst navigating geographical challenges. Gender equity can be supported by NBS technologies, and these must be leveraged urgently to fight social and cultural challenges that prevent girls living with NCDs enjoying well-being on par with their neighbours and fulfilling their right to life and health.

Applying the Economic Lens: Cost-Benefit Analyses of NBS

Speaker: Ms Emma Santini

- Intern - International Paediatric Association
- CLAN Project Officer - @MATES4Kids
- Former CLAN Youth Representative to the United Nations

Ms Emma Santini presented on economic analyses of NBS for CAH, exploring financial underpinnings of implementation and scaling. The need for economic analyses of this kind arises from the low prevalence and high mortality of CAH, similar to other congenital disorders, and subsequent disproportionalities in treatment in resource-poor settings. For instance, NBS coverage in the Asia-Pacific region reached 95% of high-income countries, but less than 5% in low-middle income countries. Economic analyses are vital to ensure costs are distributed in a way that effectively manages NBS amidst other public health concerns. Where limited financial resources are a barrier to NBS, a lack of funding results in a lack of treatment, including medical professionals, equipment and medication. Such concerns must be addressed in light of SDG 8 'Decent work and economic growth'.



Economic analyses can be divided into two categories. Cost-Benefit Analyses consider whether economic benefits outweigh the economic costs of a given policy, providing a more comprehensive tool for assessing financial viability in the long-run. Comparatively, Cost-Effectiveness Analysis considers the cost in proportion to output of a policy, focussing on contrasting spending to a given outcome.

Examples of academic works focused on economic analyses include:

- *The Cost-Effectiveness of Congenital Adrenal Hyperplasia Newborn Screening in Brazil: A Comparison Between Screened and Unscreened Cohorts*" Costa de Miranda et al. (2021) - This study concluded that NBS 'appears cost-effective', with an incremental cost-effectiveness rate (ICER) of \$25,535 per life-year saved.
- *Cost-Effective Analysis of the Congenital Hypothyroidism Screening Program in Sri Lanka*" Karunarathna & Hettiarachchi (2021) - This study concluded that there is 'proven effectiveness' in light of the economic impact of a lack of early detection and a benefit-cost ratio of 3.6.

What is a common thread from this discussion is that NBS for CAH not only saves lives, but money too, further creating a more economically efficient and healthy society. Economic analyses are vital in ensuring that evaluations are well-informed. However, the human aspects of NBS are of utmost importance, regardless of cost-beneficiality.

Panel Discussion

Moderated by Sienna Gates and Sofia Rousseau:

Ms Marika Mayrdorfer-Muhr

- *Co-Founder, CAH Austria*
- *Co-Founder, CAH International*
- *Nurse; lived experience expert*



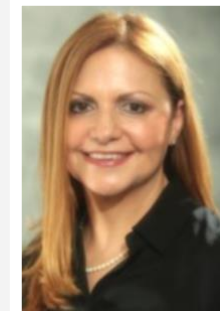
Professor Dianne Webster

- *Vice President, International Society for Neonatal Screening*
- *Task Force for Newborn Screening Member, International Federation of Clinical Chemistry and International Society for Neonatal Screening*
- *Member, Clinical and Laboratory Standards Expert Panel on Newborn Screening*



Ms Dina Matos

- *Executive Director, CARES Foundation*
- *Founding Member, CAH International*
- *Published guidelines for the development of centres of excellence for CAH and designated 8 of these centres across the US*
- *Collaborated in the development of CAHtalog*
- *Supported the development of the Preventing Adrenal Crisis Events (PACE) app*



This panel discussion centred around the global coverage of NBS programs, and steps needed to expand this reach, with a specific focus on CAH as an example.

Where NBS is limited in resource-poor settings, children experience inequitable access to healthcare and disproportionate social and financial burdens. Progressions in NBS in high-income countries have transformed the lives of children and families living with chronic health conditions such as CAH, through earlier diagnosis and improved medical care, thereby optimising quality of life. NBS promotes equitable healthcare for all and is an essential tool for reducing health disparities - especially for children and families in resource-poor settings. Collaborations and partnerships will be essential to scaling effective implementation of NBS technology globally.

Ms Marika Mayrdorfer-Muhr highlighted the importance of NBS for the international CAH Community. Whilst NBS has been present in Austria and Europe for approximately 40 years, availability and accessibility is not as advanced in resource-poor settings. Given that the discovery of the CAH occurred in the 1930s, and treatment progressions largely were achieved in the 1950s, the risk of adrenal crisis and death for newborns with CAH is now significantly reduced through NBS. Notably, early diagnosis also allows women and girls with CAH to find their identity and sense of self, a vital aspect of wellbeing and health.

Ms Dianne Webster provided an analysis of conditions and coverage of NBS on a global scale. Whilst much progress has been made and is cause for celebration, much is left to achieve.

NBS currently covers a total of 39million babies a year – which sounds like a lot, but only represents 28% of the estimated 140 million babies born each year (see **Figure 7**).

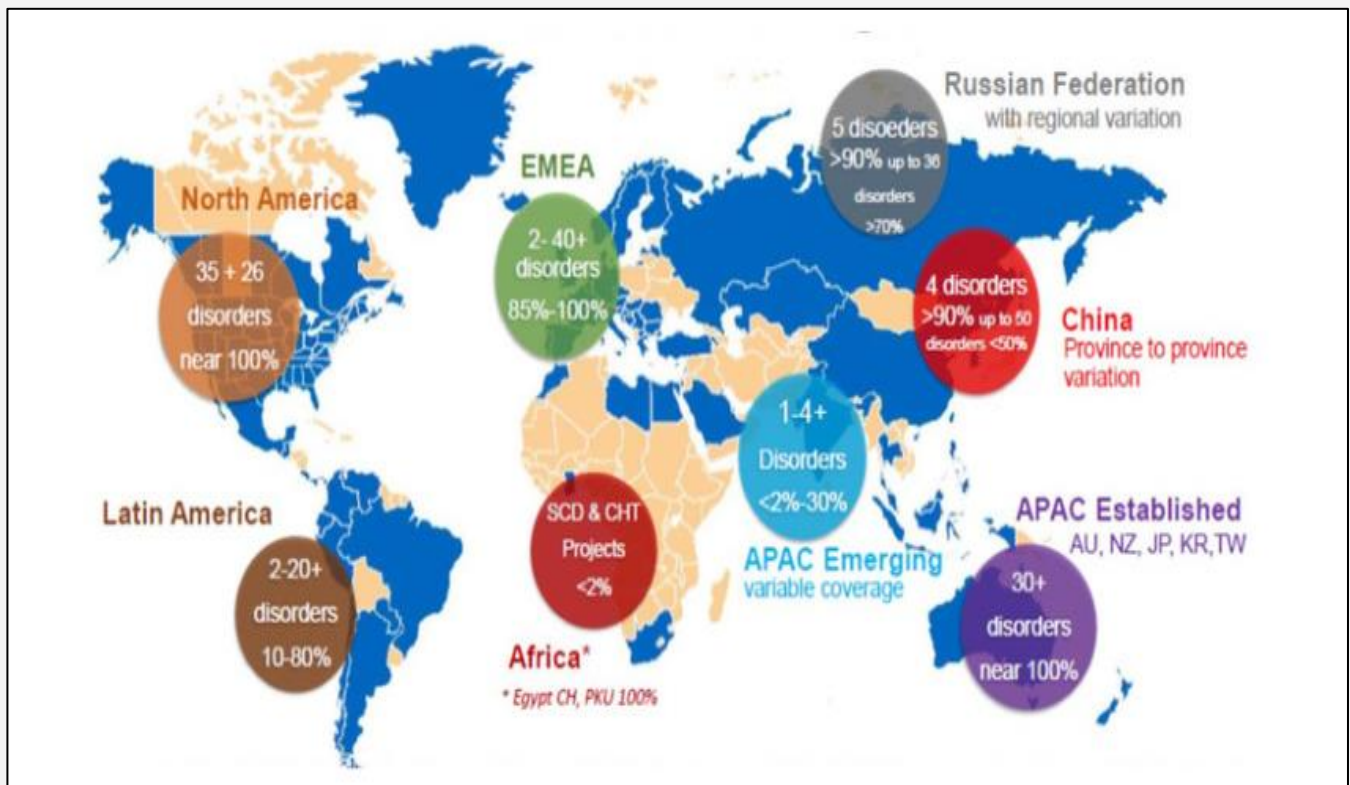


Figure 7 - Global NBS Map; Prof James Bonham, President of International Society for Neonatal Screening

Ms Dina Matos built upon the importance of NBS in the context of CAH. In the US, most states report participation in NBS of 99.99% or higher, with screening available for more than 60 disorders currently, and approximately 1 in every 300 newborns screened eventually being diagnosed. Globally, health organisations in 113 countries perform NBS, but there is still a long way to go to ensure equitable access. In the context of CAH, NBS is the most common route of diagnosis, and the condition often requires immediate treatment. Where rare diseases such as CAH are not correctly diagnosed, impacts are long-lasting, and create burdens for caregivers, healthcare systems and society. Diagnostic delays have repercussions for individual, community and economic health, and represent an unmet medical need. NBS is inherently the first step to achieving the early diagnosis of rare diseases and improved health outcomes. Improved adoption of NBS programs can only be achieved through a coordinated multi-stakeholder approach from leaders of patient organisations, government, industry, medical services, academia and healthcare services.

Globally, the availability of NBS is disparate. From 12 out of 15 countries in Southeastern Europe, only 1 test for CAH. In Brazil, the NBS program was created in 2001, with testing for PKU without governmental directions. By 1980, 55% of babies were screened. Screening for CAH began in 2011, however, issues with results were dependent on a variety of factors such as socio-economic status and geography, as well as age at diagnosis. Ms Matos concluded that attention to the facts and outcomes of NBS underscore an urgent need to modernise the NBS system. The next step, following CAH NBS, is whole-genome sequencing, which would result in first-time accurate results, saving costs and lives.

More NBS Success Stories from the CAH Community

With thanks to CARES Foundation and families involved for sharing!



Figure 8 - Jessica's Story

Watch [here!](#)



Figure 9 - Kaitlin's Story

Watch [here!](#)



Figure 10 - Cara's Story

Watch [here!](#)



Figure 11 - Alex and Owen's Story

Watch [here!](#)



Watch videos from the CARES Foundation [here!](#)

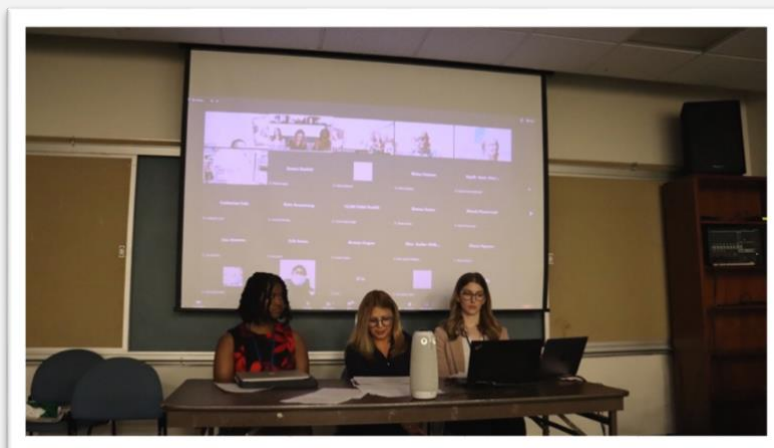


Figure 11 - Sofia Rousseau, Dina Matos and Grace Strik, CSW67, New York 2023

Conclusion

Speakers:

Ms Grace Strik

- Youth Advisor (Governance Support), CLAN
- Assistant Treasurer, CLAN
- Secretary, CLAN Risk & Audit Subcommittee

Ms Sienna Gates

- Youth Advisor (Community Outreach), CLAN



The primary theme for the 67th Session on the Commission of the Status of Women is **“Innovation and technological change, and education in the digital age for achieving gender equality and the empowerment of all women and girls”**. When framing the Priority Theme of the CSW67 in light of the work of CLAN and the @MATES4Kids movement, it is clear that NBS will have a large role to play in achieving the SDGs. NBS is a proven, effective technology, which prevents child morbidity and mortality, and allows for early intervention, ultimately improving the lives of children and families living with NCDs. Noting mothers and girls experience an especial burden associated with NCDs in resource poor settings, NBS has the potential to contribute to gender equality.

TARGET 3-2



END ALL PREVENTABLE DEATHS UNDER 5 YEARS OF AGE

TARGET 3-4



REDUCE MORTALITY FROM NON-COMMUNICABLE DISEASES AND PROMOTE MENTAL HEALTH

In order to achieve the SDGs by 2030, it is clear we must improve access to essential medicines, scale newborn screening programs, and strengthen communities. CLAN’s CSW67 event aimed to address the disparities in access to healthcare services and essential medicines for children, particularly girls, in resource-poor settings and low-income families. The event’s discussions were aligned with the United Nations Sustainable Development Goals (SDGs), notably:

- SDG 3 (Good health and wellbeing)
- SDG 5 (Gender equality)
- SDG 10 (Reduced inequalities) and
- SDG 17 (Partnerships for the goals).

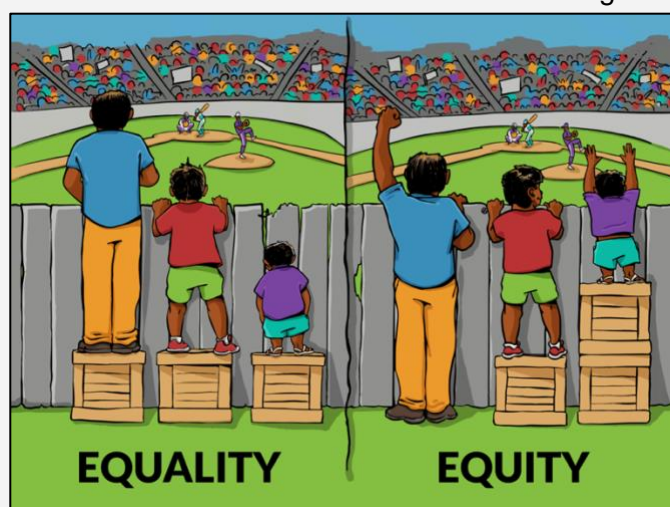


Newborn screening and early detection of medical conditions can prevent developmental delays, disability, and death. The mortality rate among children living with chronic health conditions, including congenital adrenal hyperplasia (CAH), in resource-poor settings remains unacceptably high despite the widespread development and cost-effectiveness of newborn screening technology. To address this issue, there is a pressing need for more equitable distribution of this technology, coupled with comprehensive education of families and healthcare professionals to raise awareness of the importance of early detection and treatment. Newborn screening presents a particularly valuable opportunity to reduce the psychosocial burdens of girls living with CAH. It is crucial to ensure girls maintain their right to prosperity of life while upholding cultural sensitivity.

Notwithstanding the quality of newborn screening technology available, the current status of implementation and availability of newborn screening in resource-poor settings is discordant with principles of equitable healthcare, and does not match need with regards achieving the SDGs by 2030. It is unacceptable that children in LMIC experience an inequitable burden of disability and death due to the sub-optimal utilisation and availability of this developed technology. **An equity lens must inform efforts to scale NBS globally**, and drive investment in the innovation, technological change and education that will be needed to achieve gender equality.

The discussions at CLAN's CSW67 event highlighted the urgent need for a comprehensive approach to sustainable change that includes improving access to essential medicines, scaling up newborn screening programs, and strengthening communities to achieve the SDGs by 2030. Action on any one of these strategies alone will be insufficient and unsuccessful. To achieve the potential benefits of newborn screening technology in their entirety, it will be crucial to ensure families, healthcare professionals, and policymakers are educated and aware of its importance. Likewise, efforts to improve access to medicines must involve and privilege the voices and perspectives of people living with NCDs. Cross-sectoral collaborations and partnerships between different stakeholders such as government, businesses, academia, and civil society will be needed to achieve the SDGs. In this regard, a supportive ecosystem is required, enabled by policies and regulations that facilitate universal health coverage for children and families living with NCDs.

CLAN's Strategic Framework rests upon the diagnosis of children with NCDs, and is optimised through early diagnosis. Following diagnosis, children and communities can be connected with others living with the same condition and supported to enjoy the highest quality of life through a collaborative focus on CLAN's five pillars. As such, the role of universal NBS programs is critical.



Activity 3 - Delivery of an oral statement by CLAN's UN Youth Representative

CLAN is grateful to our wonderful UN Youth Representative **Nikki Pasterczyk** for sharing 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 CSW67 on Thursday 16 March at the United Nations, and we share a copy of Nikki's speech as well as a [link](#) to the video recording.



“Good morning, my name is Nicole Pasterczyk and I am a student at Lehigh University and a UN Youth Representative for the Australian NGO Caring and Living as Neighbours (CLAN) and the @MATES4Kids movement. I am also speaking to you as the sister of a sibling living with a rare non-communicable disease, phenylketonuria, diagnosed by newborn screening.

An NCD is a chronic health condition that lasts a long period of time and is not transmittable. Examples of childhood NCDs include Type 1 diabetes, cancer, asthma, congenital hypothyroidism and congenital adrenal hyperplasia.

In many low- and middle-income countries, girl babies face increased risks associated with NCDs. Girls often experience inequitable access to care and less aggressive treatments, which increases their risk of complications and denial of their basic human rights to life and health. In most cases, mothers, women, are left as primary carers of children with such conditions.

*When affordably available for **every** newborn child, newborn screening overcomes gender inequities as it does not discriminate against girl babies. A simple heel-prick blood test can help diagnose a broad range of treatable NCDs. Newborn screening technology is already developed, and just needs to be scaled into healthcare systems equitably if we are to leave no child behind.*

40 million babies are born each year, yet only 1 in 3 receive screening of any type. It is unacceptable that newborn screening is not yet uniformly available to all.

My question to the panel is: what advice do you have for civil society, in the lead up to the UN High Level Meetings on Universal Health Coverage in September 2023 and Noncommunicable Diseases in 2025, and delivery of the SDGs in 2030, to support efforts to scale universal coverage of newborn screening so that we leave no child behind?”

Thank you to CLAN's Young Leaders!

So much hard work and planning went into making CLAN's involvement in #CSW67 such a huge success.

CLAN sincerely thanks **Sofia Rousseau, Nikki Pasterczyk, Sienna Gates and Grace Strik (left to right in photo below)** for their commitment to making a difference for children and young people living with CAH and other NCDs in resource poor settings – you truly are great @MATES4Kids!



Next Steps and Recommendations from @MATES4Kids

Meaningful steps must be taken to reduce preventable mortality by CAH by 30% by 2030. The @MATES4Kids movement proposes a collective, global and strategic focus on efforts to:

1. Improve access to essential medications and equipment

Affordable access to CAH and childhood NCDs medications must be achieved for every country and considered within the initial planning phases of every NBS Program. Systems must be in place to ensure families of children diagnosed with NCDs are not bankrupted by health expenditures. It is a fact that countries have introduced NBS Programs without first ensuring the medicines needed to treat the condition/s are affordably available. This is a tragedy for the families that are most affected.

Access to medication and equipment is a central focus of the @MATES4Kids movement and the first pillar of CLAN's Strategic Framework for action. It is an absolutely essential requirement for every child diagnosed with an NCD. Access to essential medicines requires specific efforts by Member States, with all steps in place at the national, regional and local levels to achieve uninterrupted supply chains. Even when medicines are already included in the WHO Essential Medicines for Children List (WHO EMLc) or National Essential Medicines Lists (NEMLs),

@MATES4Kids acknowledges the majority of families of children living with NCDs in resource-poor settings are unable to affordably access essential medicines. Economic analyses similar to those discussed in relation to NBS will help demonstrate the economic benefits of ensuring people living with NCDs can access the medicines and care they need to survive and thrive.

2. Strengthen CAH and other childhood NCD Communities

In line with CLAN's Strategic Framework for Action, **quality of life** for children diagnosed with CAH and other NCDs must be improved through a holistic, sustainable community development approach that addresses the bio-psycho-socio and cultural needs of families.

Even for children diagnosed with NCDs in resource-poor settings who have access to medication, multiple other barriers to a quality of life on par with their neighbours in wealthier countries exist, and must be redressed. CLAN's Strategic Framework for Action outlines the need for a comprehensive community development approach that calls for collaborative action on education, research, advocacy, optimisation of medical management, community support groups and freedom from poverty if children living with NCDs are to enjoy the highest quality of life possible.

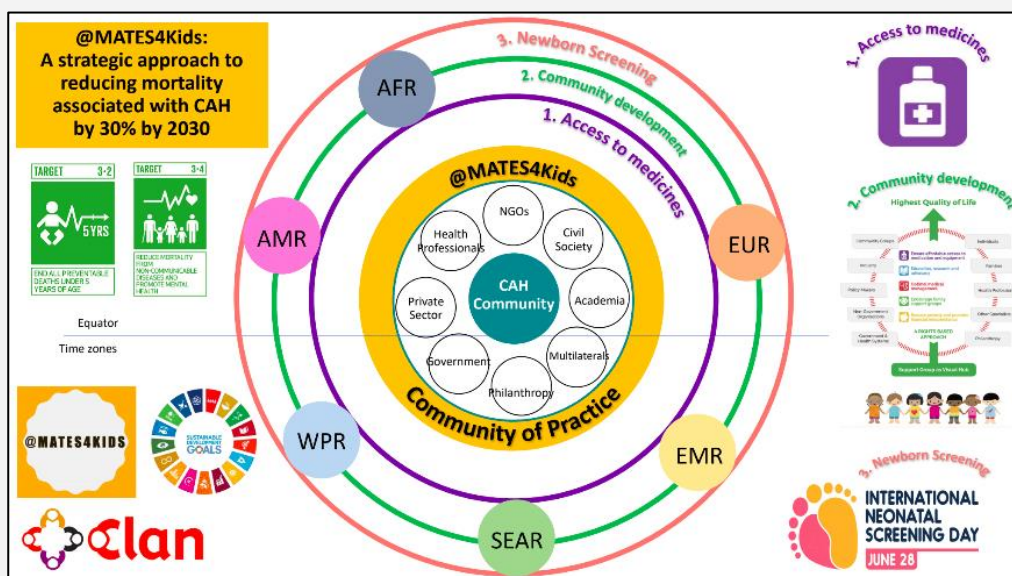
A rights-based approach to advocating for children living with NCDs will help drive change, and highlights the vital need to redress social barriers such as stigma. A rights-based approach facilitates consistent dialogue on the attainment of basic needs, and justifies calls for equity measures that can track efforts to optimise quality of life for all.

Two-way training and education that raises awareness of the needs and perspectives of children and families living with NCDs will ensure not only that medical management is optimised and medications are used appropriately, but also that those with the greatest need are better represented and their voices are informing changes within and to health systems, and improving outcomes and reducing preventable mortality and morbidity. Community Support Groups are a necessary component of achieving the highest quality of life for all. Empowered NCD communities benefit children and families as much as they do health professionals and health systems.

3. Scale newborn screening

NBS must be **scaled** globally, with an equity lens informing implementation. Inclusion of NBS in the development agenda and universal health coverage discourse is critical. Governments must invest in NBS technology along with accountability measures to ensure the best outcomes and equitable use of resources.

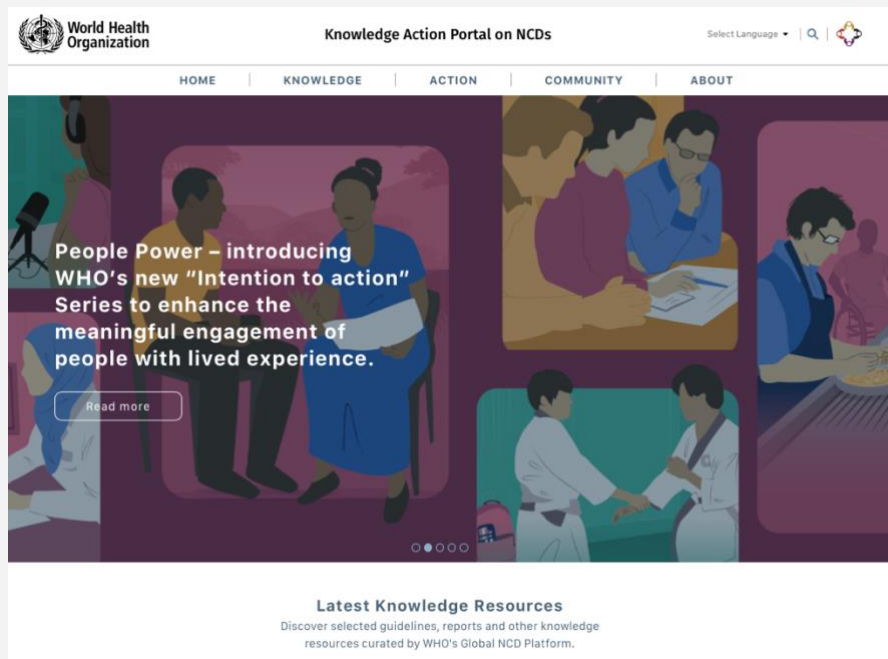
In order to scale NBS, active dialogue surrounding available technology and its effectiveness are required. To facilitate this dialogue, data outcomes in resource poor settings must inform an evidence-based approach, and remind policy makers of the benefits of NBS. This dialogue ultimately needs to culminate in an international agreement on the implementation of newborn screening. The upcoming United Nations High Level Political Forum on Universal Health Coverage in September 2023 offers an appropriate platform for reaching international agreement, and promoting global dialogue and advocacy for newborn screening. It is essential that newborn screening be included on the development agenda, and integrated within the broader call for universal health care. Real change will only be achieved when governments invest in NBS technology. Screening for congenital hypothyroidism must be the first priority, as this is more common than CAH and contributes enormously to the burden of developmental delay globally. However, as has happened in all high-income countries, expansion of NBS panels to include other NCDs such as CAH will soon follow. As NBS Programs are progressively scaled, accountability measures must be in place to ensure evaluation and monitoring ensures the best outcomes and use of resources.





Thank you so much to EVERYONE involved!

For more information on the work of the @MATES4Kids movement please visit our Community of Practice platform on the WHO's Knowledge Action Portal:



<https://knowledge-action-portal.com/en>



Don't forget to support #INSND 2023 on 28 June this year!