

2022-23 Annual Report



An opportunity
to live a healthy
and happy life with
Osteogenesis
Imperfecta



Caring & Living As Neighbours

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On 27 May 2011, CLAN was formally accepted as a signatory to the Australian Council For International Development (ACFID) Code of Conduct. CLAN is committed to improving international development outcomes and increasing stakeholder trust through enhanced transparency and accountability.

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

CLAN seeks to ensure all we do is ethical, transparent, and underpinned by integrity. Should there be a time when we are not seen to be acting in this way, a complaint can be lodged with the President of CLAN or the CLAN Executive Committee in accordance with our Complaint Management Policy.

Should there ever be a time when CLAN is not seen to be acting in accordance with the ACFID Code of Conduct to which we are signatory, contact can be made with the ACFID Code of Conduct Committee at <http://www.acfid.asn.au/code-of-conduct/complaints>.

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About Us

What is CLAN?

Caring & Living As Neighbours (CLAN) is an Australian not-for-profit, non-government organisation (NGO), approved by AusAID for Overseas Aid Gift Deduction Scheme (OAGDS) status and endorsed by the Australian Taxation Office (ATO) as a Deductible Gift Recipient (DGR).

CLAN's Vision is that all children living with chronic health conditions in resource-poor countries of the world will enjoy a quality of life equivalent to that of their neighbours' children in higher-income countries.

CLAN's Mission is to maximise quality of life for children and their families who are living with chronic health conditions in resource-poor settings of the world.

An innovative network bringing communities together to drive change

Since 2004, CLAN has pioneered a person-centred, rights-based community development approach that places children, their families, and carers at the heart of the solution, bringing local and global communities together to support each other.

CLAN's model is built around five pillars of action:

1. Affordable access to essential medicines and equipment
2. Education (of patients, families, health care workers, government bodies, policy makers and the international community), Research, and Advocacy
3. Optimal medical management (with a focus on preventive and holistic care)
4. Encouragement of family support groups
5. Promoting financial independence and reducing the financial burdens on families that lead to poverty.



CLAN's Strategic Framework for Action

CLAN is proving that by working together, it is possible to effect change on a global scale for children living with chronic health conditions. It is vital that we all strive for this, because children and families themselves are virtually powerless to effect change without the support of neighbours, friends, health care professionals and concerned global citizens.



President's Report

As we approach our 20th year, it's an important time to reflect not just on the year that has been, but also the road ahead, and the direction in which we seek to travel.

CLAN's 2023-2030 Strategic Plan has set us three key objectives:

- to establish and support the @MATES4Kids Movement so that it can achieve its goal of reducing the preventable mortality associated with CAH by 30% by 2030
- to promote implementation of CLAN's Strategic Framework for Action and
- to advocate for inclusion of a focus on children and young people who are living with and at risk of NCDs in the post-2030 development agenda

With this in mind, there is no doubt 2022- 2023 has been a very successful period. @MATES4Kids is now firmly established as an internationally recognised entity promoting collaborative action to reduce the preventable mortality associated with CAH. Encouraged by early wins (with donations of medicines to Zimbabwe, Ukraine and more recently Sri Lanka); emboldened by the Briefing Paper presented to WHO (Feb 2022) and guided by three clear objectives (to improve access to medicines, strengthen CAH communities and scale Newborn Screening), @MATES4Kids held our first hybrid meeting at the IMPE (International Meeting for Pediatric Endocrinology) in Buenos Aires in March 2023. With participants from around the world (including paediatric endocrinologists, CAH Community members and PAHO (Pan American Health Organisation) representatives), the @MATES4Kids network agreed on future ways of working collaboratively to achieve our old goals.

Since meeting in Buenos Aires, @MATES4Kids has continued hosting quarterly Community of Practice meetings; co-hosted a parallel event at the UN CSW67 in New York; participated in the 2023 UN Science Summit; presented written and oral statements at the UN High Level Political Forum and International Day for Women and Girls in Science respectively; and established a Community of Practice on the WHO's Knowledge Action Portal for NCDs. It's been a busy year, and our inaugural @MATES4Kids Activity Report (now available on the KAP) is definitely a celebration of what's possible when everyone works together.

On that note, it's vital that CLAN acknowledges the many partners, volunteers and friends who make all of this possible. We are so grateful to our many donors and sponsors, and thank them for their belief in CLAN. We also welcome our new partners, Great Cherry, and are excited about the great things we will achieve together in the future!

Young people continue to be at the forefront of the work of CLAN. We have been extremely fortunate to have some wonderful DFAT New Colombo Plan Scholars volunteer for us in the Asia Pacific Region; our Lehigh UN Youth Representatives continue to assist us with our engagement in UN processes and events; and our team of Youth Advisors continue to build our capacity as a not-for-profit, non-government organisation. Together, we are supporting partners in a range of countries to implement CLAN's framework and five pillars, and scale rights-based, community development initiatives to optimise quality of life for children living with chronic health conditions.

We are grateful to everyone for their generous contributions. Looking ahead, there is so much to look forward to. Whilst we are on a tight timeline – 2030 is just around the corner – we are confident that our collective advocacy and action can and will continue to make a difference. Together we can #LeaveNoChildBehind.

Committee Members

Founder and President – Dr Kate Armstrong

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



Vice President - Cath Cole

Cath is the Vice President of CLAN. She has enjoyed a long career in government and has developed skills in several areas including policy development, project management, program development, development and delivery of education and training, and preparation of foundational documents such as strategic and business plans.

Inspired by the work of CLAN, Cath was the Secretary from the time CLAN was incorporated as an independent Association through the Department of Fair Trading for four years and since 2011 has been active in the role of Vice President supporting and promoting the work of CLAN.



Treasurer – Joseph Hansen

Joe was appointed Treasurer in 2018, having volunteered for CLAN over many years, most notably travelling with our team to Vietnam, Fiji, and the Phillipines to meet with some of the communities we work with. Joe has completed a Bachelor of Commerce and is currently undertaking his Chartered Accountants qualification while working at a Big Four accounting firm. Joe enjoys playing Cricket and Australian Rules Football in his free time.



Secretary – Marilyn Hansen

Marilyn has been acting as the Secretary for CLAN for many years, involved in the vital aspects of maintaining CLAN's administration and compliance with oversight bodies. Marilyn views her work as supporting governance to allow other members to plan and implement CLAN's mission and strategic framework. Marilyn has previously worked in Early Childhood teaching, continuing her teaching career predominantly in High School settings. She was then appointed as Associate Education Director for the private school system in New South Wales. Marilyn's extensive career in this sphere has shaped her extraordinary abilities in supporting CLAN to this day.



Public Officer – Dr Laura Colenbrander

Laura is the most recent addition to the committee team, having been appointed in 2022 as Public Officer. Laura is a doctor currently training in psychiatry, a field she is passionate about. Outside of work, Laura particularly enjoys travel and netball. Laura has loved supporting CLAN through some editorial work.



Ordinary Members

Maria Craig



Maria Craig's major research interest lies in childhood diabetes, including studies focused on the prediction and prevention of Type 1 Diabetes. Maria is increasingly concerned about the association between viruses and Type 1 Diabetes, a shared area of interest which is identifiable in her collaboration with the Virology Research Group. She is the principal investigator for the CoRD trial, a world first Phase 1 study, utilising autologous cord blood for the prevention of Type 1 Diabetes in children with islet autoimmunity. Maria is the Medical Director for the Australasian Diabetes Data Network and the President-Elect of the Asia Pacific Paediatric Endocrine Society (APPEs).

Honorary Member: Angie Middlehurst



Angie Middlehurst is one of CLAN's Ordinary Members, and this year we are proud to award her Honorary Membership also.

Angie is a passionate advocate for global insulin and diabetes supplies access, management of diabetes at school, diabetes camps and supporting the transition from paediatric to adult care for children and young people with Type 1 Diabetes. Angie's background lies in General and Paediatric Nursing, where she has been involved in efforts to support the community impacted by childhood Diabetes for 26 years. Angie played a vital role as Deputy Manager and Education Director for the Life of a Child (LFC), a program based at Diabetes NSW in Sydney, Australia from 2011-2018.

Though now semi-retired, Angie continues to engage her essential knowledge and exposure to the issues of diabetes through volunteer work, including here a Caring and Living as Neighbours (CLAN). Her generous and giving nature also continues to extend to others through her volunteer work for a range of global diabetes organisations: International Society for Paediatric & Adolescent Diabetes (ISPAD), Life For a Child (LFAC), International Diabetes Federation (IDF), Insulin for Life Global (IFL), Juvenile Diabetes Foundation of Australia (JDRF), PenPals United USA (PPU) and DiAthelete. This year, Angie was the nominated mentor for the APPEs-CLAN Grant Programmes undertaken. Notably, Angie has recently been awarded the IPSAD Lestrade award for Education and Advocacy, which is to be announced at the IPSAD virtual meeting in October 2021.

Angie Middlehurst has been a long-time friend and supporter to CLAN's work. Initially supporting our efforts for children living with Type 1 Diabetes (during her time with Children's Hospital Westmead as a Diabetes Nurse Educator, first with Children's Hospital Westmead and later Life For A Child), Angie has travelled with CLAN's team to attend Diabetes Club Meetings in Vietnam and Pakistan. In more recent years Angie has been an invaluable member of CLAN's Working Committee, attending meetings, mentoring projects internationally and providing technical advice to our in-country project officers. CLAN thanks Angie most sincerely for her invaluable contributions over many years.

Guiding Principles

CLAN's guiding principles inform all of our activities and initiatives. Such values related to CLAN's work include:

Children first – children and young people living with chronic health conditions will always be the central focus of all that CLAN does.

Care - love of neighbour drives a passion for justice and equitable quality of life for all.

Community development - grass-roots communities are the visual hub of CLAN's strategic framework for action, and a recognised driver of sustainability and empowerment.

Family - prioritising a person- and family centred approach, CLAN celebrates the strength, passion and commitment families can bring to initiatives to drive long-term change.

Health for all – CLAN is committed to leave no child behind in global public health efforts and supports calls for Universal Health Coverage.

Human rights-based approaches – inform all of CLAN's activities, notably the United Nations' Convention on the Rights of the Child and Declaration on the Rights of Indigenous Peoples.

International – CLAN works in many different countries around the world, and privileges the voices and perspectives of those from lower income settings.

Indigenous control – in all of CLAN's work with and for Indigenous Communities, we are committed to Indigenous Community Control at all times.

Investing in people – CLAN's programs prioritise education and training as a means to improving knowledge and practices, and optimising health outcomes.

Partnership – building creative and trusting relationships with the people in the countries we work creating an inclusive, collaborative, flexible and responsive approach wherever possible.

Professionalism – ethical and transparent program management processes, including evaluations of activities and resources, ensure best practice and optimal outcomes are achieved.

Respect – in its relationships with partners and participants, and acknowledgement of unique histories and cultures of countries we work, respect is a basic element of all programs and initiatives.

Sustainability – CLAN's programs strive to achieve sustainable outcomes to promote economic and environmental sustainability of communities and groups we partner with; we promote self-reliance to minimise dependency and optimise health outcomes for all.

Equity - commitment to health for all, and the concept that every child living with NCDs might have everything they need to enjoy the highest quality of life possible. In many instances, this will require action that privileges those living in the most vulnerable circumstances.

@MATES4Kids

Maximising Access to Essential Supplies for Children

<https://www.mates4kids.org/>

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

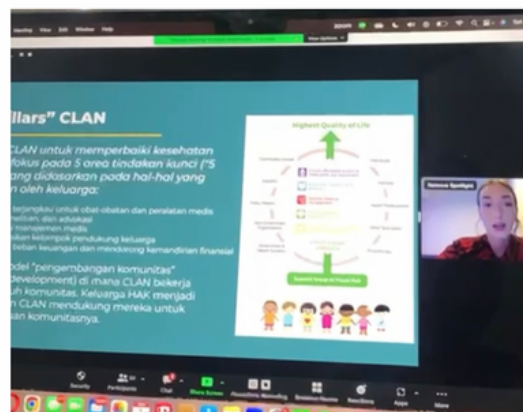
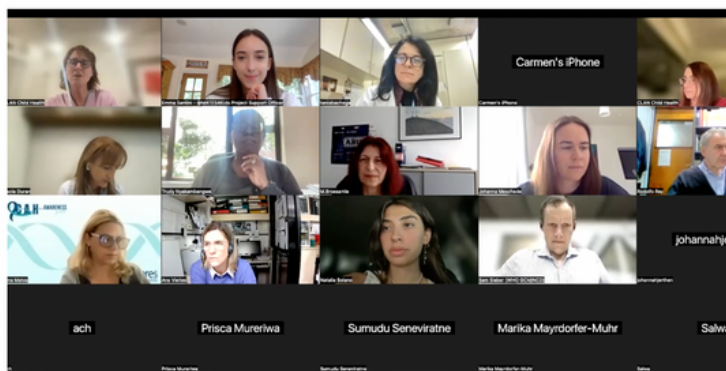
in resource poor settings. With an initial focus on Congenital Adrenal Hyperplasia (CAH), the most common adrenal condition of childhood, @MATES4Kids is seeking to leverage achievements by the childhood cancer and Type 1 diabetes communities to achieve the goal of reducing the preventable mortality associated with CAH by 30% by 2030. This mission focuses on targeting three key areas: improving access to essential medicines, strengthening community development and scaling newborn screening (NBS).



MAXIMISING ACCESS TO ESSENTIAL SUPPLIES FOR CHILDREN

Community of Practice Meeting

The foundation of the @MATES4Kids mission relies on developing a Community of Practice (CoP), defined by Etienne Wegner as a “group of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly.” The new CoP will bring together a broad range of stakeholders from around the world. @MATES4Kids recognises the World Health Organisation's (WHO) 6 regions – Africa (AFR), Americas (AMR), Eastern Mediterranean (EMR), Europe (EUR), Southeast Asia (SEA), Western Pacific (WPR) – and will call upon champions from each region to facilitate and scale action locally. More broadly, the CoP will foster seamless collaboration and regular dialogue between a global network of stakeholders to drive practical action. The CoP has committed to meeting quarterly (3 regions reporting each quarter to enable each region to report twice a year) with monthly check-ins. CLAN is proud to share that the first @MATES4Kids CoP meeting was a huge success, with inspiring presentations from colleagues in Colombia, Brazil, Germany, Zimbabwe, and Sudan (representing the AMR, EUR, and AFR regions) who shared about their progress, pearls (strengths), priorities, and partners. For instance, the tangible actions being taken as a result of @MATES4Kids coordination can be exemplified by Dr. Paola Duran's achievement of 97.5% response rate on the CLAN snapshot survey in Colombia, as well as her work on a recently developed GPED survey on access to medicines that has already been distributed between Mexico, Argentina, Bolivia, and Colombia.



IMPE: International Meeting of Pediatric Endocrinology

@MATES4Kids truly gained momentum following the 11th International Meeting of Pediatric Endocrinology (IMPE) on March 4, 2023. @MATES4Kids hosted a hybrid event, "Strategic Planning Meeting: Practical steps to improve access to essential CAH medicines," which focused on bringing key stakeholders together to inform a course of collaborative action through sharing successes and challenges. With 16 attendees in-person and many others online, seeking endorsement on proposed next steps emerged as a key objective. The meeting included an overview of the @MATES4Kids movement, presentations from partner organizations (International Commission of Pediatric Endocrinology, Global Pediatric Endocrinology and Diabetes, and the Pan-American Health Organization) updates from pediatric endocrinologists across the globe, and a general discussion among attendees to map what is next for @MATES4Kids.



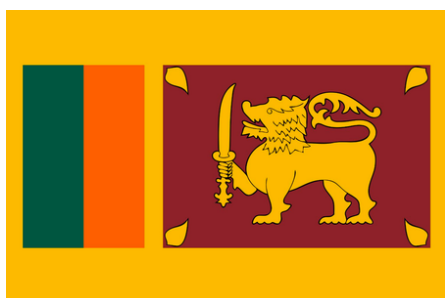
Meeting delegates at the Global Paediatric Endocrinology and Diabetes (GPED) Stall

The event, as well as CLAN's presence at the conference, garnered an outpouring of support for @MATES4Kids and generated interest in participating from pediatric endocrinologists across the globe. Since the IMPE meeting, the coalition has steadily added passionate health professionals to the network and built capacity for long-term, multisectoral collaboration.



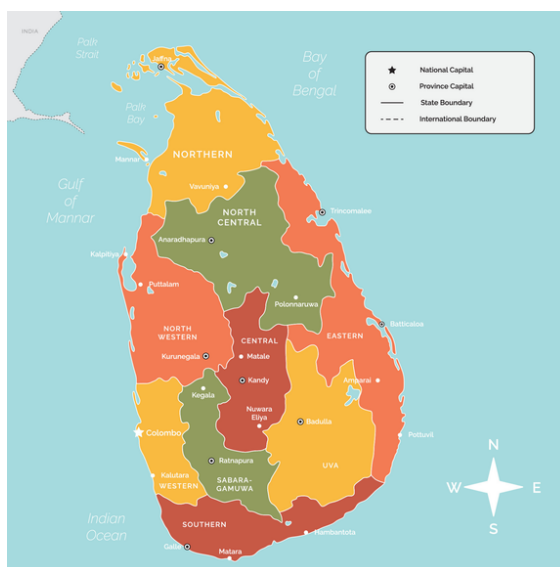
The first face-to-face @MATES4Kids Working Group meeting was held in Buenos Aires on 4 March 2023.

Sri Lanka



In 2022 CLAN received a request from paediatric endocrinologists in Sri Lanka for assistance securing access to hydrocortisone and fludrocortisone tablets for the 200+ children living with CAH in their country. The financial crisis in Sri Lanka was threatening access to affordable essential medicines, and families living in the most disadvantages circumstances were particularly vulnerable.

With thanks to the CAH Community of Germany and Binden Pharma in Pakistan (manufacturers of high quality, affordable hydrocortisone and fludrocortisone tablets), CLAN was able to courier a one year supply of enough medicine to treat at least 30% of all children with CAH in Sri Lanka for a 12 month period. The medicines arrived safely in Sri Lanka in March 2023, and doctors in Sri Lanka have been distributing the medicines to those children and families in greatest need. Sincere thanks to all involved in making this wonderful international collaboration possible!



Members of the @MATES4Kids Secretariat



Carmen Auste – Co-Chair

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

Emma Santini - Project Support Officer

Since completing her internship with CLAN, Emma Santini has continued to work with CLAN by supporting @MATES4Kids as Project Support Officer. In her new position, she is grateful to play an active role in the establishment of this exciting initiative and support the coalition as it grows and evolves. While she frequently contributes to strategic planning, risk assessment procedures, and meeting preparation, her responsibilities also largely focus on the organization and management of the @MATES4Kids Community of Practice on the WHO Knowledge Action Portal. She works directly with WHO to develop the online platform so it may become the best possible home for long-term multistakeholder collaboration. Emma shares that she is inspired by the efforts of doctors and CAH community members who are coming together from across the globe to truly make a difference in the lives of children everywhere. She is humbled by the opportunity to create a space for these changemakers that facilitates such impactful discourse and exchange of information.

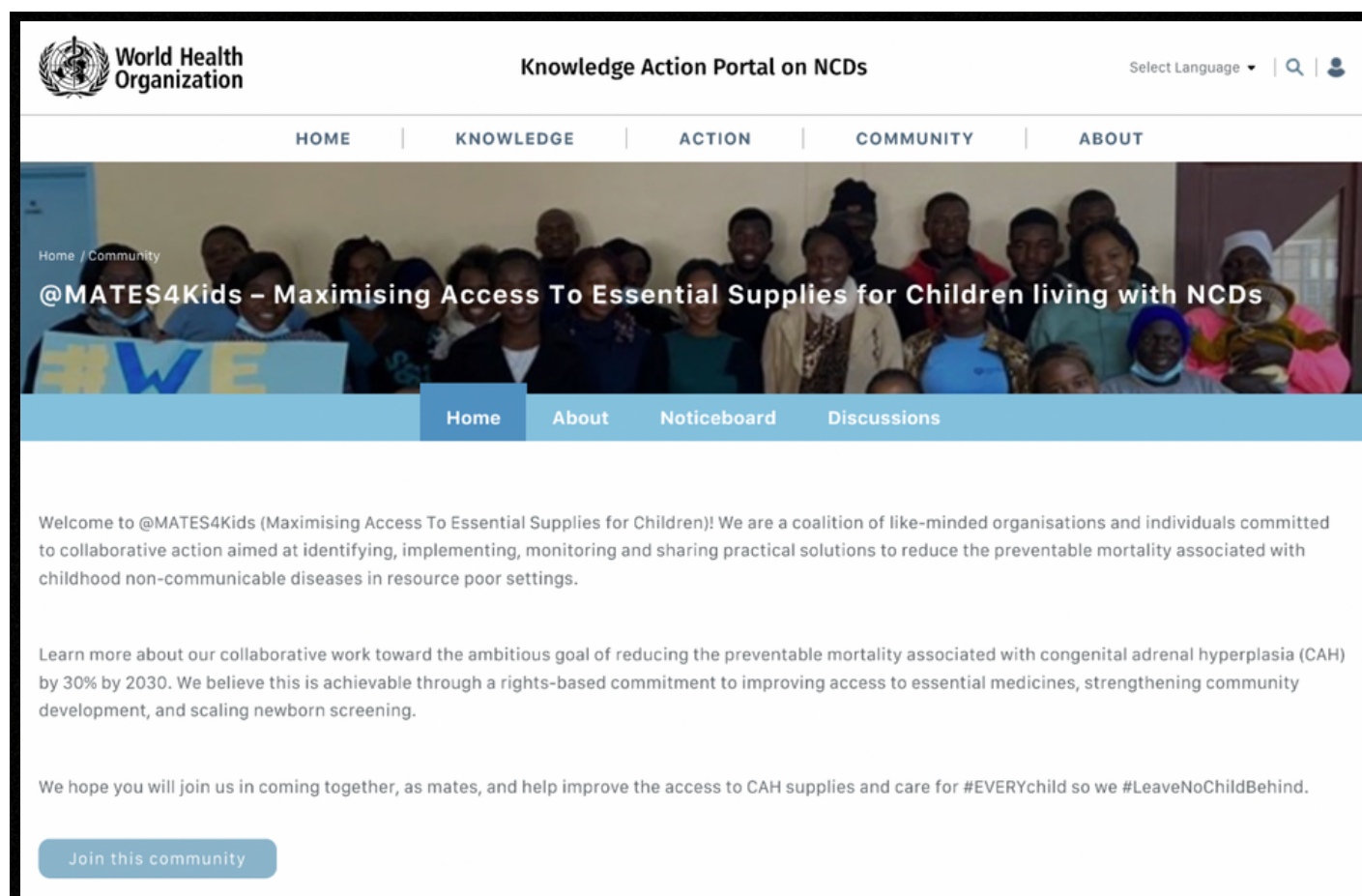


Rabia Baloch – Research Officer

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

Knowledge Action Portal

@MATES4Kids uses the [WHO Knowledge Action Portal](#) (KAP) on NCDs as the primary platform for connecting the CoP. According to WHO, the KAP is defined as a “knowledge sharing and community platform dedicated to enhancing NCD prevention and control through multisectoral and multistakeholder collaboration.” The @MATES4Kids CoP page on the KAP houses a variety of functions. It is a space to easily read up on the coalition’s mission and access supporting documents. Through noticeboard posts, community members can share resources, make announcements, spotlight important updates, and provide other valuable insights to the group. This section of the KAP will ultimately help highlight success stories and motivate members of the CoP by celebrating each and every accomplishment. Where there are topics that require discourse, and help is needed to overcome a hurdle or clarify an uncertainty, the discussion page will facilitate conversation among members allowing them to post their thoughts and leave comments. Overall, members can turn to the KAP for the @MATES4Kids CoP’s updates, resources, announcements, and achievements, making it an important resource that is currently being expanded and scaled.



The screenshot shows the WHO Knowledge Action Portal on NCDs. The header includes the WHO logo, the title "Knowledge Action Portal on NCDs", and a "Select Language" dropdown. The main navigation bar has links for HOME, KNOWLEDGE, ACTION, COMMUNITY, and ABOUT. The page is titled "@MATES4Kids – Maximising Access To Essential Supplies for Children living with NCDs". Below the title is a blue bar with links for Home, About, Noticeboard, and Discussions. The main content area welcomes visitors to @MATES4Kids, describing it as a coalition of like-minded organizations and individuals committed to collaborative action aimed at identifying, implementing, monitoring and sharing practical solutions to reduce the preventable mortality associated with childhood non-communicable diseases in resource poor settings. It also mentions the goal of reducing the preventable mortality associated with congenital adrenal hyperplasia (CAH) by 30% by 2030. At the bottom, there is a "Join this community" button.

World Health Organization

Knowledge Action Portal on NCDs

Select Language ▾ | 🔍 | 👤

HOME | KNOWLEDGE | ACTION | COMMUNITY | ABOUT

Home / Community

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

Home | About | Noticeboard | Discussions

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

Learn more about our collaborative work toward the ambitious goal of reducing the preventable mortality associated with congenital adrenal hyperplasia (CAH) by 30% by 2030. We believe this is achievable through a rights-based commitment to improving access to essential medicines, strengthening community development, and scaling newborn screening.

We hope you will join us in coming together, as mates, and help improve the access to CAH supplies and care for #EVERYchild so we #LeaveNoChildBehind.

[Join this community](#)

CLAN Community Development Officer - Dr Andrew Twineamatsiko

I am privileged yet again to share the successes and achievements of CLAN Child Health Africa over the last year. We have indeed learnt and expanded on our partnerships and impact within the region adding an extra Country of operation-Burundi.

Uganda continues to implement activities that improve the livelihood and health of Children living with Epilepsy. Currently the support group has established stronger links with the healthcare workers with an added commitment of a Paediatrician and the Paediatric Neurologist. This will

improve quality care offered in this system. The leadership team will be focusing on the Advocacy pillar in the next year with a planned stakeholder engagement for all involved in care of children living with Epilepsy including the families and caretakers.

The Zimbabwe team has grown into a stronger CAH community with active involvement in the CAH Community of Practice and the availability of the previously donated medicines has played a strong role in the access to medicines pillar.

The last year also saw us visit Burundi and launch a community support group for Children living with Type-1 diabetes. The relationship between the Burundi NCD Alliance and the project team will further propagate the efforts of strengthening the established support group. Efforts are also underway to improve on the education of both community members and health workers towards improving health and care.

We are still deeply committed to continue supporting all communities in the region to ensure that all Children access proper care and all their rights using the Rights-based community approach. Special thanks to the CLAN team; locally and in Australia, all our in-country partners, the health workers as well as the patient groups we work with to achieve success.

To all partners and stakeholders who continue to support our efforts and reach in the region, we appreciate you all and look forward to another amazing journey in this coming year.

Dr Andrew Twineamatsiko
Community Development Officer





In 2023 Child and Youth Care has been influential in making CAH community access fludrocortisone and hydrocortisone medication for free at Sally Mugabe Children's Hospital. In 2023, the organization has helped families in accessing CAH medications for free at Sally Mugabe Children's Hospital. CYC has worked closely with other partners in making a difference for the CAH community for instance having a wonderful long-term partnership with doctors has improved the quality of care. Through regular meetings with staff from CYC Zimbabwe and Sally Mugabe Children's Hospital a call for workplan on how to improve the quality of life of CAH community was drafted. CLANs donation of fludrocortisone and hydrocortisone medications in April 2022 have continued to be a great source for the community through 2023.

In commemorating CAH awareness month, CYC shared a broad range of existing educational material that could be shared with families. The campaign was targeted towards community building and raising awareness of CAH more broadly in Zimbabwe. In addition, using social media, CYC used WhatsApp group where the organisation hosted CAH experts that is the pediatrician, psychiatrist, and mental health counselor. These medical experts enlightened all our group members including CAH community members with essential information of CAH condition in two of our local languages.

This year 2023, the organization has partnered with Zimbabwe Medical Students Association who runs a program rare diseases initiative in raising awareness on CAH on their own platforms using slide shows and power point presentations to school each other.

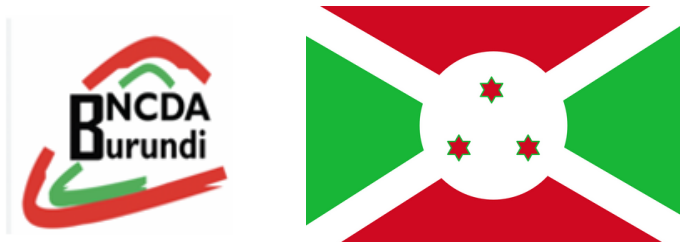


The use of support groups is another way of supporting CAH communities as it allows sharing of ideas and knowledge among members thereby building relationships. CYC made significant efforts in forming CAH family support groups that consist of CAH families. With the formation of family support groups, it can be noted that CAH families managed to make connections and relationships that help in minimising harm caused by isolation and stigma. Meetings are currently being combine with other families living with rare diseases.

CYC managed to form a group where CAH families are being trained in entrepreneurship so that they can sustain themselves. So far 4 of our CAH families have been selected to be part of the poultry project which is starting early this month of July 2023. The poultry project is meant to economically capacitate CAH families so that they can sustain themselves thereby doing away with donor dependency syndrome. This project will also fund the medical fund which is currently struggling.



The Diabetes Community of Burundi



CLAN Child Health Africa was proud to partner with the Burundi NCD Alliance (BNCDA) to support community development initiatives with and for children and families living with Type 1 Diabetes (T1D) in Burundi. Access to medicines and equipment have been generously supported by Life For A Child, so CLAN's collaborative efforts with local partners in Burundi have largely focused on efforts to help the community grow stronger. Initiatives to date have included T1D community meetings and educational sessions, as well as a formal health needs assessment to inform a stronger understanding of the challenges experienced by children and families. There are currently no paediatric endocrinologists in Burundi, so another key priority has been to support local health professionals to engage in international paediatric endocrinology training opportunities. Throughout the 2023 financial year, CLAN provided funding to the Diabetes community in Burundi to undertake a range of activities, in partnership with the Burundi NCD Alliance.

In April 2023, an breakfast meetings occurred with the MoH/NCD unit to organise a high-level advocacy meeting with children living with T1D, their parents, members of the MoH, the BNCDA and other members of the civil society. The aim of this meeting was to share children's stories about their struggles with T1D including difficulties with education, societal stigma, financial hardship, and lack of access to other monitoring medical equipment.



High-level meeting with children living with T1D, their parents, members of the MoH, members of the BNCDA and other civil society members.

In May 2023, the project team led by Damien Nkenguburundi, carried out regular education and screening for children and other patients living with diabetes in May 2023, alongside Deogratias, T1D clubs, and the education club coordinator. Throughout June 2023, the BNCDA team, Professor Barasukana and Professor Francois conducted a training of local health care provided on T1D management guidelines, during monitoring and evaluation activities.



BNCA team, Professor Barasukana and Professor Francois conducted a training of local healthcare providers in Citiboke on T1D management guidelines.



Deogratias, T1D clubs and the education centre coordinator carried out education and screening for adults and children living with diabetes in Citiboke.

Indonesia



Wishbone Day 2023

"Why is Wishbone Day Important? Because awareness makes a difference." – Wishbone Day motto.

In May 2023, Wishbone Day celebrations with FOSTEO resumed for the first time since 2018. Wishbone Day is an annual awareness-raising day for the international Osteogenesis Imperfecta (OI) Community, and is celebrated every year on the 6th of May. On the 21st of May 2023, 28 families gathered to celebrate Wishbone Day, with members of FOSTEO and the Indonesian OI Community travelling from all over the Java Island to attend the RS Pondo Indah Hospital outdoor garden and community playground. This event was supported by CLAN (Caring & Living As Neighbours) and Yayasan Kesehatan Anak Global (YKAG).

This event consisted of an educational seminar for parents, a Q&A session with special guests Professor Aman Pulungan and Dr Dana Prihadi, a painting class for the children, and sharing session led by six parents of children living with OI. The educational seminar focused on valuable knowledge related to clinical aspects of OI, including holistic management, essential medicines, and tips for enjoying a happy and healthy life with OI. This event was a great opportunity for families to learn more about OI, share their experiences and motivate one another. At the event, families were provided with educational booklets developed by YKAG and CLAN, which included CLAN's OI Child-Friendly Rights Flyer.

Celebrations of Wishbone Day are an opportunity to amplify the voices of OI communities across the globe and join with them in celebration of the achievements of all people living with OI. Awareness of OI in the wider community creates a dialogue throughout society, inviting others to get involved in driving practical change for people living with OI so we all enjoy our basic human rights of life to health, happiness and wellbeing.

To learn more about the FOSTEO's 2023 Wishbone Day Event, you can access the full report written by CLAN Intern Téa La on CLANs website through this link -

https://www.clanchildhealth.org/uploads/8/3/3/6/83366650/fosteo_wbd_2023_celebrations_final.pdf.



Event organizers chose to conduct the meeting in the form of a seminar which allowed for several important conversations surrounding CAH. Topics of focus included clinical aspects of CAH, administering drugs to CAH patients at home, monitoring CAH in children and adolescents, the importance of mental health support, efforts both domestically and abroad to improve access to CAH medicine, and overall progress made in the field thus far. Speakers included Vahira Waladhiyaputri as MC, KAHAKI leader Borneika Sharri, Executive Director of the International Pediatric Association (IPA) and well-known pediatric endocrinologist Prof. Aman Pulungan, pediatric endocrinologist Dr. Ghaisani Fadiana, and project support officer for CLAN/Mates4Kids Emma Santini.

CLAN, KAHAKI and YKAG were thrilled to reach a total of 125 participants dialing in from 12 different provinces across Indonesia. Throughout the event, parents were actively engaged and curious to know more about CAH. Parents asked an abundance of questions in the chat and several attendees chose to participate with their video turned on. Furthermore, there was a notably high volume of questions asked via the registration form prior to the event. Overall, this group of parents displayed an inspiring resilience and strong commitment to better understanding their child's CAH diagnosis. CLAN feels incredibly proud to support this community and looks forward to future collaboration. The CAH online event made history as the first virtual CAH community meeting in Indonesia, demonstrating that despite the well-known benefits of families coming together and interacting face-to-face, there are myriad new opportunities offered by online formats waiting to be embraced and cultivated.

The poster is for a hybrid educational event titled "KELAS EDUKASI HIPERPLASIA ADRENAL KONGENITAL (HAK)". It features logos for CLAN, YKAG, and KAHAKI at the top. The event is free ("GRATIS") and scheduled for Saturday, 1 April 2023, from 09.00 to 11.00. It offers both offline (at Gedung IDAI) and online (via Zoom) participation. The topics will be presented by Dr. Ghaisani Fadiana and Emma Santini. Registration is open for 25 offline and unlimited online spots. QR codes for registration are provided, along with a list of sponsors including Prodia.

GRATIS

CLAN YKAG KAHAKI

**KELAS EDUKASI
HIPERPLASIA
ADRENAL
KONGENITAL (HAK)**

Acara Hybrid: Offline untuk 25 Peserta dan Online via Zoom

Offline: Gedung IDAI
Jl. Salemba I No. 5, RT. 4/RW. 6, Kuning, Kec. Senen, Kota
Jakarta Pusat, Daerah Khusus Ibukota Jakarta 10350

Online: Via Zoom Meeting
Pukul 09.00 - 11.00

SABTU, 1 APRIL 2023

Topik Narasumber

Dr. Ghaisani Fadiana, SpA(K)
Tipe dan Tfb Mengobati Anak dengan
Hiperplasia Adrenal Kongenital

Emma Santini, S.A
Upaya Internasional dalam
Peningkatan Akses Pengobatan HAK

Link Daftar Offline

Registrasi kegiatan offline terbatas untuk 25 pendaftar pertama
Link Pendaftaran Offline: bit.ly/KelasEdukasiHAK
Registrasi kegiatan online (via Zoom) jumlah peserta tidak terbatas.
Link Pendaftaran Online: bit.ly/KelasEdukasiHAKOnline

Link Daftar Online

Sponsored by: Prodia



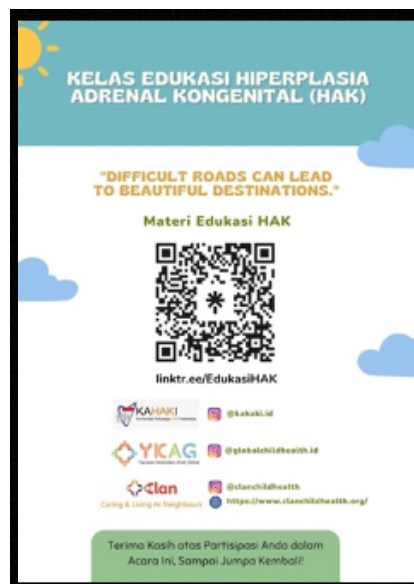
CAH Online Event

In Indonesia, Komunitas Keluarga HAK Indonesia (KAHAKI) serves as the primary CAH family support network, where members have been coming together since 2008 to foster close connections with one another, share resources and knowledge, and ultimately improve the circumstances for children living with CAH across the nation.

CAH requires consistent long-term management. With proper management and care provided, CAH patients live long, happy, and healthy lives. However, there are still many parents, caretakers, and patients, who do not understand various aspects of the condition and its treatment. This is why KAHAKI chose to partner with CLAN and Yayasan Kesehatan Anak Global (YKAG), an Indonesian foundation created to improve child health, to plan a CAH parenting class for the community. Meetings such as these are critical in promoting greater knowledge, awareness, and confidence in managing CAH, while also providing an outlet for families to interact with each other, as well as medical professionals.

Understanding the vast potential of CAH club meetings, event organizers focused on achieving the following four goals:

1. Educate parents of CAH patients on how to properly manage their child's condition and promote the best possible health outcomes.
2. Discuss the latest facts regarding CAH in Indonesia such as access to essential medicines and newborn screening.
3. Facilitate a space where families of CAH patients feel comfortable communicating with each other and with medical professionals.
4. Conduct CQI to respond to the CAH community's ever-changing needs.





Indonesia Diabetes Camp 2023: Batu, East Java

In the beautiful surroundings of Batu, Indonesia, the first of two Diabetes Camp in 2023 commenced with great success. From 24-25 June, 50 young people living with Type 1 Diabetes (T1D), along with 24 family members, all from IKADAR, the Indonesian diabetes community, came together to participate in this important support and education event. The tireless efforts of the Changing Diabetes in Children (CDiC) Indonesia team and local health professionals afforded towards the great outcome. CLAN are incredibly honoured to have young intern, Téa La, attend and closely observe the activities. Additionally, Téa worked with the local health professionals to conduct a diabetes Health Needs Assessment (HNA), a vital part in identifying the experiences, needs and priorities of families with children and young people living with T1D. The Indonesian Pediatric Society (IPS) reported 1,249 children and young people living with T1D in Indonesia between 2017 – 2019. It is predicted that the true burden of T1D in Indonesia is underestimated, due to missed diagnoses and the urgent need for increased awareness and education of families, health professionals and policy makers alike. Through multisectoral collaborative efforts, such as the CDiC program, we can effect real change for all children and optimise their quality of life.

The Diabetes Camp was hosted at the Kusuma Agrowisata Resort & Convention Hotel, utilising two spacious halls and the outdoor setting amidst nature. It was an opportunity for the young people to have fun and gain valuable knowledge about managing their diabetes. Through engaging games, they not only bonded with other young people but also learned about essential aspects of diabetes self-management, including metabolic control, nutrition, physical activity, and diabetes-related complications. While the young people engaged in interactive diabetes-related games, their parents and guardians attended an education workshop. Led by local paediatric endocrinologists, paediatricians, and nutritionists, the workshop provided insights into diabetes management and the diabetes case in Indonesia.

Following a day full of education and activities, everyone gathered over delicious food. This was the perfect opportunity for young people, and their families to mingle. The day ended with a sharing session and motivation training, where a sense of mutual support and understanding could empower the community. The morning of the final day at the camp was filled with outdoor games and activities for the young people. Tapping into their competitive spirits and energetic selves there was even a unique experience to harvest guava fruit. With no diabetes-specific activities, the outdoor games and guava harvest promoted physical activity and further strengthened the bonds between the young people.





In the lead up to the Diabetes Camp, Téa collaborated with community leaders Anita Sabidi, Faith Amasowomwan, Elizabeth Pfiester, and Arif Novianto, and caring health professionals Professor Aman Pulungan, Doctor Amelia Gassani and Angie Middlehurst to create a Diabetes Newsletter. The newsletter was disseminated to participants at the Diabetes Camp and the broader IKADAR network. The newsletter was developed as a tool for communication, sharing of information, raising awareness of CLAN's Strategic Framework For Action, privileging the voices of the local and international diabetes community, and encouraging active engagement. The newsletter was made available in the Indonesian language, ensuring accessibility to all IKADAR members and relevant stakeholders. The translation of materials is credited towards the efforts of Emma Santini and Vahira Waladhiyaputri.

After the education workshop was held, a diabetes HNA was conducted in collaboration with CLAN, parents, guardians, the CDiC team, IKADAR and local health professionals. This HNA aims to highlight the unique insights of the challenges and burdens faced by families with children and young people living with T1D in Indonesia. This is essential to informing practical actions and collaborative approaches to redress inequities. Led by Téa and Dr. Erlisa Devi, the parents and guardians participated in the survey. Data will be analysed, and a report disseminated to all stakeholders in the coming months. The Diabetes Camp 2023 in Batu, Indonesia, was a remarkable event for all who attended and for Téa to observe. The dedication of the CDiC team, the commitment of health professionals, and the enthusiasm of the participants came together to create a positive experience for the children and young people living with T1D. CLAN are looking forward to seeing and hearing future community events.



Rights Flyers

CLAN is excited to share that two Child-Friendly Rights Flyers have been updated over the past year. Téa La, Community Development Officer, developed the OI Child-Friendly Rights Flyer in partnership with Jo Ragen, and in consultation with the international OI community, to align the flyers with recent advocacy efforts. The OI Child-Friendly Rights Flyers have been translated into Indonesian and Korean. This OI Flyer was launched on Wishbone Day 2023. Grace Strik, Youth Advisor, has also updated the CAH Child-Friendly Rights Flyer, and its release is anticipated late 2023. Child Friendly Rights Flyers support advocacy efforts and helps children and young people understand their basic human rights as declared under the United Nations Convention on the Rights of the Child. CLAN extends its thanks to the passionate partners involved with the flyer who are committed to engaging in collective advocacy efforts to highlight and protect the rights of every child.

골형성부전 (Osteogenesis Imperfecta, OI) 환아의 권리로 무엇이 있을까요

전 세계 모든 어린이는 동등한 권리를 가집니다. UN 아동권리협약
(United Nations Convention on the Rights of the Child, UNCRC 1989)
에서 이러한 권리를 선언한 바 있습니다. 국제 사회는 그 어떤
어린이도 그러한 의료 서비스를 받을 권리를 박탈당하지 않도록 할
의무를 가집니다.

UN은 모든 어린이가 사회 안에서 개별적인 삶을 온전히 살 수 있어야 하며 행복, 사랑,
이해, 평화, 존엄, 관용, 자유, 평등, 연대의 정신으로 양육되어야 함을 선언합니다.

세계보건기구(World Health Organisation, WHO)는 모든 어린이(OI 환자 포함)가 차별
없이 '최상의 건강 수준' 및 복지를 누리고 질병 치료와 재활 시설을 이용할 권리를 가진다고
명시하고 있습니다.

골형성부전증 및 기타 만성 질환을 가지고 있는 어린이, 청소년과 그 가족은 다섯
가지 주요 활동 영역(CLAN의 다섯 가지 주요 사안)에 대한 지원을 기대합니다. UN
아동권리협약에서는 이러한 요구 사항을 모든 어린이의 권리로 인지하고 있습니다.

수용

교육

낙인 제거

의료 서비스

재활

보조기

필수 의약품

지원 보건 제공

심리 지원

골형성부전증과 함께 건강하고 행복한 삶을 살 기회



Sometimes children living with OI need access to medication such as bisphosphonates. These can help strengthen bones and prevent injuries. Children with OI can experience pain. Access to fracture care and pain management can help. Access to these medications when needed can improve health and wellbeing.

Apa yang perlu diketahui tentang OI



OI adalah kelainan genetik yang mempengaruhi produksi kolagen dalam tubuh. Sebagian besar individu dengan OI memiliki tulang yang mudah patah – oleh karena itu kelainan ini seringkali disebut "penyakit tulang rapuh".



Ada beberapa tipe OI dengan gejala yang bervariasi dari ringan sampai parah. Mutasi genetik berkaitan dengan OI yang mempengaruhi di seluruh tubuh termasuk tulang, mata, telinga, sendi, gigi, dan kulit. Anak-anak dengan OI bisa hidup dengan bahagia, sehat, dan aktif.



Akses ke layanan kesehatan seperti fisioterapi dan terapi okupasi, dapat membantu dalam: meningkatkan gerak bebas, membangun kekuatan otot, meningkatkan mobilitas sendi, pemulihan dari cedera, belajar tentang pencegahan cedera dan keamanan kegiatan sehari-hari.



Seringkali anak-anak dengan OI membutuhkan alat bantu seperti kursi roda, kerangka, dan kruk. Alat-alat tersebut dapat membantu anak-anak mendapatkan kebebasan dan kemandirian.

WORLD WISHBONE DAY - 6 MAY *@wishboneday*



Strong support groups can help children and families by fostering a spirit of happiness, understanding, dignity, tolerance, freedom and equality.

Wishbone Day is celebrated every year on 6th May to raise awareness of OI and connect OI communities around the world!

Great Cherry - Helping CLAN do great work!

This financial year, CLAN began its partnership with Great Cherry, Australia's first champion of fine robusta coffee beans, dedicated to re-defining the conception of Vietnamese robusta beans. Great Cherry's vision focuses on where and how capabilities can be applied to create the most value for others and make everyone better off.



<https://greatcherry.org>

Great Cherry is committed to donating at least 1% of sales to CLAN to facilitate access to care, medications and equipment for children living with chronic health conditions in resource-poor settings.

Will and Tami, co-founders of Great Cherry, are both originally from Vietnam. Will came to Australia to complete his Masters, and was involved in a socially responsible wine company which supported access to clean drinking water. Inspired by the knowledge that even small contributions are great drivers of change, Will knew he wanted to tread a similar path. Tami is currently a barista in Sydney, and came to understand that many Australians had never tried quality Vietnamese coffee. Having come from families who have been coffee traders and growers for many years, this was very surprising to Will and Tami. So, they decided they wanted to build a business that provides great Vietnamese Robusta coffee beans to Aussies, and gives back to the Vietnamese community where they were born and raised. Will and Tami were particularly inspired to work with CLAN, as they have come to understand the different in access to medical facilities and services between Vietnam and Australia.

Great Cherry is driving change both through their contributions to the Australian coffee market, and they their partnership with CLAN, demonstrating how business can be a force for good in society. Recently, Great Cherry launched two produced with coffee brand Campos, and this was one of the first times a large coffee brand in Australia launched Vietnamese coffee on that scale. Now, they are doing business with German partners, and in progressed discussions across other regions. And for every coffee bean sold globally, they will continue to donate at least 1% of sales to CLAN.

CLANs Youth Advisors Grace and Sienna were fortunate enough to meet with Great Cherry's cofounders, Will and Tami Nguyen, and learn more about their inspiration and motivation for reaching out to partner with CLAN. To read this interview and learn more about this partnership, visit CLANs website at – LINK. To learn more about Great Cherry, you can visit their website -

<https://greatcherry.org/>.



Youth Advisors



Grace Strik

Youth Advisor (Governance Support)
Assistant Treasurer
Risk and Audit Subcommittee Secretary

Grace is a third-year student at the University of Technology Sydney studying a Bachelor of Laws (LLB), Bachelor of Business (Accounting), and Diploma in Languages (Japanese). Grace is a Legal Clerk and academic tutor. Outside of work, Grace enjoys reading and exercising, and is passionate about learning as much as she can. Grace is responsible for coordinating the work of the Youth Advisors, organising materials for the Risk and Audit Subcommittee, preparing draft Treasury updates to report to the Committee, assisting the Committee and Association meeting minutes, and assists on an ad hoc basis across the organisation. Her general responsibilities include conducting interviews with CLAN members, preparing social media and website content, meeting with various stakeholders and providing administrative, governance and substantive support as projects arise.



Sienna Gates

Youth Advisor (Project Support)

Sienna is a second-year pre-medicine student at the University of Wollongong and has been working with CLAN for just over two years. Her role with CLAN is as a project support youth advisor, working closely alongside the other youth advisors as well as president Dr. Kate Armstrong and vice president Cath Cole. Her main roles with CLAN include promotion and outreach for projects and events, website maintenance, project support and the production of CLAN's newsletters. Sienna's work with CLAN has allowed her to create connections with many inspiring people with a similar drive for positive change. Her work in the social media space has allowed her to tune in to events, conferences and workshops worldwide that help deepen her knowledge of the impacts of NCDs and the inextricable links between health, wellbeing, community and culture.

International Women's Day

On the 8th of March, 2023, CLAN Youth Advisors Grace Strik and Sienna Gates had the exciting opportunity to attend the Observance of International Women's Day on behalf of CLAN at the United Nations General Assembly Hall in New York. At the observance, inspiring speakers addressed the importance of gender equity within the realm of technology, innovation and STEM, and engaged with the theme of "DigitALL: Innovation and technology for gender equality". Our Youth Advisors felt fortunate to have had the opportunity to celebrate such an important cause alongside 1,800 other women, leaders and supporters of the gender equity movement.





Eloise Hansen

Youth Advisor (Community Outreach)

Eloise is a student at Macquarie University studying a Bachelor of Commerce and a Bachelor of Arts, majoring in both Marketing and Consumer Insights and Modern History. Eloise has recently been involved in social media and content creation for CLAN, using these platforms to raise awareness for CLAN's mission and organisational activities. She is excited to be involved in CLAN's upcoming Youth Advisor projects.



Simon Maleš

Youth Advisor (Project Support)

Simon is a second-year student at Western Sydney University studying a Doctor of Medicine. Simon works as an academic tutor, and enjoys playing soccer and basketball outside of work. Over the past year, Simon has worked with the CLAN team to review and update the COVID-19 educational resources, specifically developing a new infographic in vaccinations. Simon has also assisted with technical aspects of the website, and looks forward to maintaining his connection with CLAN as he works towards being a medical doctor.



Veronika Maleš

Youth Advisor (Governance Support)

Veronika is a Fifth-Year Law and International Studies student at the University of New South Wales, Sydney, who has completed an overseas exchange in Milan over the past year. She is passionate about helping children with chronic illnesses due to her lived experiences with several chronic health conditions since childhood. Veronika is a member of the Risk and Audit Subcommittee has been actively monitoring regulatory and legislative changes to assess their implications for CLAN's activities.

Lehigh University Partnership

CLAN and Lehigh University have enjoyed a long-term partnership, with dedicated Lehigh students representing CLAN at the United Nations at various events in support of the many communities we work with internationally. Our current UN Youth Representatives are Nikki Pasterczyk and Sofia Rousseau.

Nikki Pasterczyk



Nikki Pasterczyk was selected in June 2022 to act as a United Nations Youth Representative for CLAN. She is part of the class of 2025 at Lehigh University studying for a B.S in Molecular Biology to pursue medicine and research. She likes to write, hike, research, and explore new places and meet new people.

Nikki started her involvement with CLAN's United Nations High Level Political Forum (UN HLPF) in July 2022. From there on, she has drafted statements on behalf of CLAN and presented at CLAN's Parallel Event at the 67th UN Commission on the Status of Women (CSW67) focused newborn screening towards gender equality for disadvantaged girls with NCDs. She attends UN conferences at the headquarters in New York City often and has offered a verbal statement at the UN CSW67 side event on overlapping emergencies in March 2023.

"Representing CLAN allows me to volunteer for an organization that fights for resources and awareness for children with NCDs from disadvantaged communities. I am thrilled to be a part of this amazing organization, especially because my brother has a rare inherited genetic disorder and I have seen first-hand the significance of early detection and resources. I want to play a role in providing for indigenous and disadvantaged children & families, such as finding means of which to expand newborn screening to underserved populations globally. This is a one of a kind experience that will allow me to properly advocate for these groups as a future physician and researcher."

Sofia Rousseau



Sofia Rousseau is from New York City and is pursuing a Bachelor of Science in Population Health with a double minor in Maternal and Child Health and Global Studies from Lehigh University with a certificate in Global Citizenship. Upon graduating in 2025, she intends to pursue a career in nursing. Sofia was selected in October 2022 to work with CLAN as a United Nations Youth Representative.

Sofia's time with CLAN began with planning for CLAN's Parallel Event at the 67th UN Commission on the Status of Women (CSW67). This event focused on highlighting the importance of equitable access to newborn screenings worldwide. Young girls in resource poor countries in the global south are especially at a disadvantage given gender biases. Her work with CLAN thus far has pushed her towards viewing health care from a globalised context.

"Being a United Nations Youth Representative for CLAN has been a wonderful experience. CLAN is unique in the sense that they utilize a community based approach when tackling Non Communicable Diseases(NCD's) in resource poor countries. This approach is excellent because involving the communities will lead to more impactful long lasting solutions. Seeing all the wonderful work CLAN does globally motivates me to keep pursuing a career in health. I want to be a nurse in the United States because here Black and Hispanic women face disproportionately high rates of maternal mortality. It is my hope that by becoming a nurse I will one day be able to open up a clinic that serves women of color and ensure they receive the treatment they deserve. After presenting at CSW 67 I hope to go beyond the United States and help women globally. Working with CLAN has allowed me the opportunity to begin my advocacy on a global scale. This is helping prepare me to advocate for my own community one day as a nurse and advocate for equality in health care".

International Day of Women and Girls in Science

In celebration of 2023 International Day of Women and Girls in Science of February 11, CLAN shared how implementation of our Strategic Framework for Action (our I.D.E.A.!) is helping to drive change for children and families living with chronic health conditions in resource-poor settings.



In many countries, too often, girl children do not survive the diagnosis of a serious health condition. CLAN's five pillars and framework for action, which were developed in response to conversations with global communities, have since been implemented across 10 countries and more than 10 different types of chronic health condition; they have proven to make a difference to reducing mortality and morbidity.

MATES4Kids, Maximising Access To Essential Supplies, was founded through CLAN's connection and collaboration with likeminded individuals. CLAN and MATES4Kids' bold goal is to reduce CAH-related mortalities by 30% by 2030 as part of our efforts to achieve the sustainable development goals.

CLAN produced a [YouTube video](#) about the 2023 International Day of Women and Girls in Science, and promoted the hashtags #LeaveNoChildBehind and #February11 in celebration of this event.



International Day of Peace 2022

CLAN's United Nations Youth Representatives, Annie Sanchez and Nikki Pasterczyk, attended the International Day of Peace Youth Observance Event held on 16 September, 2022. Each year, the International Day of Peace is celebrated on 21 September, a day where cease fires and non-violence is observed around the globe. The theme for the 2022 International Day of Peace was "End Racism. Build Peace." The inspiring event highlighted the importance of addressing racism and discrimination to create an equitable and just world for everyone. The diverse group of speakers ranging from actors and fashion designers to researchers and students provided unique viewpoints and inspiring ideas to promote equity.

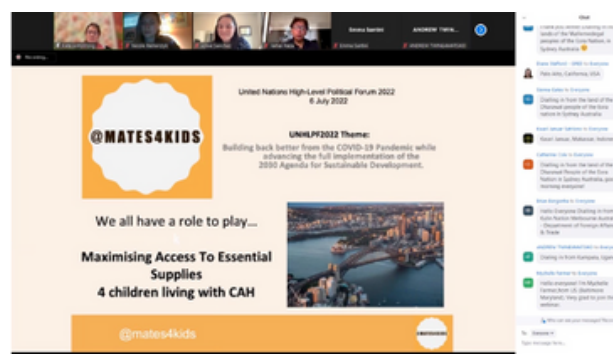
The Secretary-General, António Guterres, provided the opening remarks and spoke of the crucial role youth has as the emerging leaders to end racism and build a more peaceful world. The Under-Secretary-General for Global Communications, Melissa Fleming, followed and introduced student speakers who shared their stories growing up as an underrepresented minority in the United States. This was followed by the Blue Men Group, who did an interactive performance collecting different colored marbles from the audience. The marbles filled a clear mold that intertwined with another to display the harmony and beauty of the different colors that made up the whole sculpture. The second half of the event was then hosted by Jaden Michael, lead actor in the popular show "Colin in Black and White". During this portion, Annie and Nikki heard from diverse speakers highlighting research and projects aimed at tackling inequity. Various Indigenous speakers, such as Joan Henry, Rosario Pérez Guzmán and Arlette Silva Hernandez, talked of the importance of addressing Indigenous inequities to truly achieve a just and peaceful world.

The work of Arlette titled "Health with Equity" talked about the importance of ending discrimination and racism against Indigenous and Afro-Indigenous People in health settings. She was involved in focused on teaching medical professionals native languages, like Amuzgo, Zapotec and Mixtec, to improve communication and health treatment and outcomes for Indigenous Communities in her state of Guerrero, Mexico. The impact her work has on improving health care in Indigenous communities in her town in Mexico can provide a road map to how to best support the medical needs and improve trust between Indigenous People and non-Indigenous medical professionals. After the event, Annie took the opportunity to share with Arlette CLAN's and IndigenousNCDs work and mission of maximizing the quality of life of people living with chronic health conditions and amplifying the voices of Indigenous People in global discussions around health. We look forward to the opportunity to collaborate and hear more of her work and outcomes.



UN High Level Political Forum 2022

On July 6th 2022, CLAN presented an event at the United Nations High Level Political Forum on Building back better from the COVID-19 Pandemic while advancing the full implementation of the 2030 Agenda for Sustainable Development. The event was titled “Maximising Access to Essential Supplies for Kids (MATES4Kids): Global Multi-Stakeholder Collaboration and Partnership to #LeaveNoChildBehind.”



The event focused on the significance of partnerships towards developing innovative and sustainable solutions for medications for children living with NCDs (CAH in particular) in LMICs and MICs. The speakers represented a variety of nations and NGOs, such as Professor Jamal Raza of Pakistan, Dr. Andrew Twineamatsiko of Uganda, Trudy Nyankambagwe of Zimbabwe, Professor Aman Pulungan and Dr. Agustini Utari of Indonesia, Dr. Alicia Jenkins and Dr. Kate Armstrong of Australia, Oleg Novikov of Ukraine, and Carmen Auste of the Philippines.

The objectives of this event included raising awareness of the challenges facing children and young people living with NCDs in the context of the COVID-19 pandemic, highlight current innovative solutions to redress inequities experienced by children living with CAH, and consider how achievements to date and other recommendations might help inform efforts to build back better for the international NCD Community after the COVID-19 pandemic.

Suggested key solutions for these issues included improving local production of essential medications in LMICs to decrease costs of medications, strengthening partnerships between local communities in LMICs and the MATES4Kids network to advocate for adequate funding, resources, and information needed to effectively meet the needs of children living with NCDs, leveraging new and existing technologies (such as mobile phone apps and newborn screening) to bypass population-based barriers and enable more equitable access to essential medicines and equipment, and establishing the infrastructure (e.g. patient registers, policy changes) and innovative supply chains needed to strengthen access to essential medications despite difficult scenarios.



United Nations Youth Representative Stall at Lehigh University

On October 28th 2022, CLANs UN Youth Representatives participated in an event on campus at Lehigh University in collaboration with Lehigh's other UN Youth Representatives. The event focused on spreading awareness of UN activity on campus and how students can get involved. CLAN was joined by other organisations such as the Centre for Public Health Nigeria, American Association of University Women, the World Corrosion Organisation, and several others. CLANs UN Youth Representatives played trivia for candy with students, testing their knowledge of non-communicable diseases and the populations they disproportionately affect. Students then learned more about CLAN and how it provides resources and advocacy for children across the global, gaining a better understanding of CLANs work and its significance.



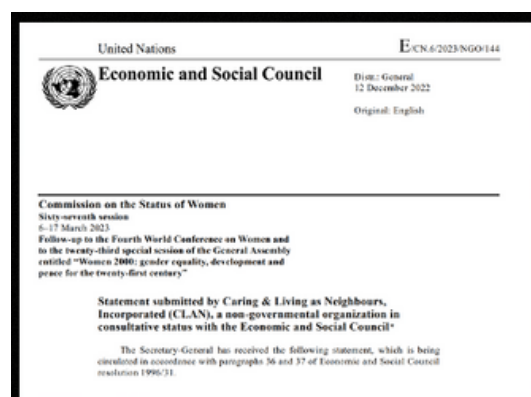
CSW67

CLAN was proud to engage in events relating to the United Nations Commission on the Status of Women 67th Session. 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'.

CLANs goal in engaging in the 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 settings of the world, and thereby contribute to the global efforts to achieve the Sustainable Development Goals by 2030.

Written Statement

CLAN was proud to facilitate the submission of a written statement to the ECOSOC that speaks to the vital role NBS can and should play in achieving the SDGs by 2030. This statement is available online through this link - <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N22/745/96/PDF/N2274596.pdf?OpenElement>



Reception to the CSW67

In anticipation of CLANs CSW67 Parallel NGO Event, CLANS United Nations Youth Representatives Nikki Pasterczyk and Sofia Rousseau, and Youth Advisors Grace Strik and Sienna Gates, were invited to the CSW67 Australian Civil Society Organisation Reception, hosted by His Excellency The Hon Mitch Fifield, Australia's Ambassador and Permanent Representative to the United Nations on the 5th of March, 2023. This event brought together the Australian delegation, civil society representatives and experts, and promoted active dialogue on issues relating to gender equality in the digital age. CLAN's team was honoured to engage in discussions with accomplished individuals passionate about improving gender equity.



CSW67 NGO Parallel Event

CLAN was proud to host hybrid Parallel Event to the commission on the Status of Women 67th Session at the United Nations Church Centre on the 6th of March 2023, and partner with global changemakers to discuss the role of 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 Development Goals (SDGs), and reduce gender inequalities affecting young girls with NCDs in resource poor settings. Speakers from Australia, Austria, Indonesia, New Zealand, Pakistan, Zimbabwe and the United States of America participated, representing a broad range of NGOs and organisations working in the field of NBS and caring for children living with NCDs.



The event began with a welcome by United Nations Youth Representative, Nikki Pasterczyk, and introduction to CLAN by Ms Sofia Rousseau. With thanks to CARES Foundation, we began the event with a success story of newborn screening, from the mother of a child with CAH who achieved diagnosis through NBS. CLANs President, Dr Kate Armstrong, then shared @MATES4Kids' mission, vision, and relationship to NBS, highlighting the integral role of NBS to achieve the @MATES4Kids timeline of reducing preventable mortality by 30% by 2030.

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



The final segment of the Parallel Event was a panel discussion between Ms Marika Mayrdorger-Muhr, a nurse with a lived experience of CAH, Professor Dianne Webster, NBS expert, and Ms Dina Matos, the Executive Director of CARES Foundation. These esteemed panellists provided an understanding of NBS around the world, and discussed how best to map a way forward. This involved contrasting the global coverage and availability of NBS, highlighting inequitable burdens faced by those in resource-poor settings, discussing technological advanced and their positive outcomes in light of NBS, reflecting on the psycho-social implications of early intervention and diagnosis, and demonstrating that there must be further work done to ensure universal access to NBS

To learn more about the event and its outcomes, or to access the video, you can visit CLANs website at this link - <https://www.clanchildhealth.org/un-csw67.html>.

Oral Statement

On March 16th 2023, CLAN United Nations Youth Representative Nikki Pasterczyk attended the United Nations 67th Commision on the Status of Women (CSW67) Interactive Dialogue Session on “Getting on track: Achieving gender equality in a context of overlapping emergencies” at the United Nations headquarters in New York City This session was to contribute to the priority theme of “Innovation and technological change, and education in the digital age for achieving gender equality and empowerment of all women and girls.”

The session presented policy options, opportunities, entry points, and lessons learned from ongoing efforts at addressing a number of specific issues facing women and girls. Nikki was invited on behalf of CLAN to present a 3 minute intervention during the interactive dialogue portion.

Nikki spoke on behalf of CLAN on leaving no children with non communicable diseases behind, especially young girls with increased morbidity and mortality from these chronic conditions in low and middle income countries. Nikki provided personal experience on living with a sibling with an NCD, as well as statistics on the gravity NCD prevalence and disparities across the globe, particularly in LMICS and MICs. On behalf of the NCD community, she advocated for increased newborn screening as innovation to reduce the inequalities for disadvantaged young girls from such backgrounds.



Interns

Téa La



Téa is a Community Development Officer for CLAN and New Colombo Plan Scholar for the Department of Foreign Affairs and Trade (DFAT). Téa has notably worked with local communities and health professionals in the Republic of Korea and Indonesia, with a focus on children living with osteogenesis imperfecta (OI) and diabetes. Téa received her bachelor's degree in Biomedicine and has future aspirations in the Physiotherapy field, where she can continue to work alongside people to help improve their well-being.

During Téa's internship in Indonesia, she assisted FOSTEO, the OI community in Indonesia, to organise the celebration of Wishbone Day 2023. Leading up to the event, she was mentored by Jo Ragen and collaborated with the international OI community to create CLAN's OI Child-Friendly Rights Flyer. At the Wishbone Day event, she spoke to young people living with OI and listened as they spoke about their daily challenges. These personal stories and encounters have further consolidated her drive to continue the efforts of CLAN.

Téa is also honoured to have attended the Diabetes Camp where she observed the fun activities held for children and young people living with diabetes and their families. She was given an opportunity to collaborate with the local diabetes community and health professionals to conduct a Health Needs Assessment in efforts to highlight the challenges and burdens faced by families with children living with diabetes.

"When I embarked on my journey with CLAN, I would never have imagined the ubiquity of opportunities that awaited me. Witnessing the heart-warming passion of families and health professionals has driven me even further to utilise my knowledge and privilege to make positive impacts on other people's lives. The unwavering dedication and tireless efforts displayed by these individuals has inspired a deep sense of empathy and commitment."

Fatima Idaayen



Fatima is a recent Psychology graduate, currently undertaking her Master of Public Health at Macquarie University. She has been working with CLAN for approximately 2 years, starting on projects at an ad hoc basis before undertaking the position of a Newborn Screening Community Development officer, working to scale and expand Indonesia's Newborn Screening Program.

As part of this she spent 6 months living in Indonesia, working with the Indonesian Paediatric Society and the Ministry of Health to support NBS efforts. A key part of her role was working on a research project titled 'Congenital Adrenal Hyperplasia (CAH): Situation and Possibility to develop a Newborn Screening Program in Indonesia- An exploratory Study. The project involved interviewing 30 parents with children diagnosed with CAH to compare experiences of late vs. early diagnosis. The overall results of the study found that when children were diagnosed early in life i.e., through NBS, they had a greater QoL, were provided access to resources and self-education opportunities and were better prepared to manage the disorder. Fatima's work in this space has prompted her to a Master's in Public Health, where she hopes to work globally to reduce health inequities and contribute to CLAN's mission of universal access to medicine and greater QoL for children everywhere. Fatima aspires to continue working globally to increase access to essential health services and resources. Please see the next page for Fatima's reflection on what it's like to intern in Indonesia.

My Experience Living in Indonesia

Fatima Idaayen



The process of applying to the New Colombo Plan Scholarship to receiving my acceptance email could not have prepared me for the fulfilling and amazing 6 months I spent in Indonesia. The 6 months were packed with amazing cultural experiences such as food and language study. I was given the opportunity to make meaningful contributions to key health initiatives and research whilst developing a life-long passion for public health.

The opportunity to live in a country with a massive geographical structure coupled with a rich history made it imperative for me to immerse myself within this environment. Visiting Yogyakarta, Bali, Belitung, Bogor, and spending most of my time in Jakarta, I witnessed the way in which history continues to weave its way into the fabrics of Indonesia today. However, something that seemed to remain consistent with all Indonesians is their embodiment of “Semoa bisa di atur”, which translates to ‘everything will work itself out’. Having grown up in Sydney all my life, this was definitely a culture shock.

My first 2 weeks in Jakarta were stockpiled with meetings, trying to organise a project in Indonesia, as well as discuss potential internship opportunities with the Ministry of Health. After much discussion, we decided that the best way to contribute to the expansion of NBS and support the Congenital Adrenal Hyperplasia (CAH) community is through shedding a light on its impacts through a research project. It focused on exploring the challenges faced by parents/caregivers of children with a late diagnosis of CAH. A late diagnosis means that Newborn Screening (NBS) was not possible at the time of the child’s birth. Child outcomes and its impact on parents/caregivers were compared with children who had the opportunity for early intervention; that is, children who had NBS coverage.

A significant event that I was delighted to have the opportunity to be a part of was the Congenital Hypothyroidism (CH) relaunch event held by the Indonesian Ministry of Health (MoH). The event emphasised the need for mandatory NBS for CH across Indonesia. Since the program’s initial launch in 2013, which saw 11 provinces adopt NBS practices, there has only been a 1% increase (from 2% to 3%) in NBS to date, creating an urgent need scale and expand the program. Contributing to this expansion process was highly rewarding and provided context for my internship with the MoH.

In anticipation of my internship with the MoH, I had the opportunity to participate in discussions surrounding NBS progress and challenges with the Minister of Health. At the time, the Health Ministry was trying to get 35,000 health professionals trained with the heel prick test by December 2022. Discussions were based around the need to develop and implement standardised training programs in most hospitals across different provinces as well as appointing a spoke person for each hospital to track progress. To achieve this purpose, biweekly meetings were set up to keep track of targets and key milestones. It was extremely interesting and fulfilling to be involved in such discussions, particularly given I was able to see the progress of those initiatives throughout my time in Indonesia.

My internship with the Ministry of Health focused on conducting policy research to identify key NBS milestones and expansion strategies to both low-to-middle income and high-to-middle income countries. Overall, my research found that the five best features of best practice for universal NBS aligned with CLANs five pillars: affordable access to medicine and equipment; education, research, and advocacy; optimisation of medical management; encouragement of family support groups ; and reducing financial burdens and promoting financial independence.





An initiative that was set up during my time in Indonesia to drive international collaboration was the Community of Practice (CoP) meetings. The meetings were a great way to communicate and share insights of NBS strategies by experts in the field between New Zealand, Indonesia, and Australia. The initiative highlighted several challenges pertaining to NBS expansion. This included logistical challenges such as establishing an effective courier system to collect and distribute samples. Further, it was highlighted that there was a massive difference in scale magnitude between the three countries; this means that strategy formulation would have to put into context Indonesia's large geographical nature. Being a part of such discussions highlighted the crucial need of international collaboration to achieve key health initiatives.

One of the first webinars I had the opportunity to contribute to was 'The Development of Newborn Screening: Moving Beyond the 1960's'. The event was extremely insightful, allowing me to reflect on the pros and cons of implementing mandatory newborn screening in countries, NBS as a holistic process and the role of health economists. Speakers highlighted the need to focus on maintaining clinical norms and trust in institutions as well as improving health care services and infrastructure. A core part of this is raising societal awareness through education and educational materials.

The UNCSW67 event with the theme 'Newborn Screening: Responding to the urgent need to leverage existing technology for gender equality' provided a fantastic and rewarding opportunity to bring my work in Indonesia to a close. Presenting on the importance of NBS for girls, it was great to share on knowledge I have gained during my time in Indonesia with attendees. Next steps include the Indonesia Council Open Conference, where I will be presenting on Indonesia's progress with NBS and the research project that is currently underway.

My time in Indonesia was more than I could have expected or asked for; I had the opportunity to make life-long friends whilst finding a passion within a field I would not have been exposed to without this experience. I am excited to continue making contributions to key health initiatives whilst supporting patients and families.



Governance Framework

Accountabilities:

In our work, CLAN proudly adheres to recognised national and international ethical practice developed and informed by the following standards:

- IFRCRC (International Federation of Red Cross/Red Crescent Societies) Code of Conduct;
- WANGO (World Association of Non Government Organisations) Code of Ethics and Conduct for NGOs;
- ACFID (Australian Council For International Development) Code of Conduct; and
- ACNC (Australian Charities and Not for Profit Commission).

CLAN proudly aligns its work and professional practice in accordance with the following:

- United Nations Conventions on the Rights of the Child;
- United Nations Millennium Development Goals;
- The Sphere Project Humanitarian Charter; and
- ACFID NGO Effectiveness Framework (June 2004)

CLAN is an Incorporated Organisation (Inc) and our activities are guided by the Article of Association (Constitution) approved by the New South Wales Department of Fair Trading and underpinned by our Operations Manual. The activities that realise the achievement of CLAN's Strategic Framework for Action are determined and monitored by CLAN's Core Committee comprising Executive members and a variable number of general committee members who are involved in project work for CLAN. Executive positions are voted on at each Annual General Meeting as per the Constitution.

CLAN Annual General Meetings are held each year, and CLAN Association Committee meetings every two months. The CLAN web-site and Annual Reports are two key mechanisms that are used for disseminating reports on CLAN's work.

CLAN Funding:

Ethical fundraising is vital to the Not-For-Profit and charitable sector if it is to provide its community and support base with confidence for its cause. The application of ethics in fundraising practice provides CLAN with the means to enter into ongoing relationships of trust with donors, supporters, volunteers and importantly, also with the beneficiaries of funds raised. CLAN seeks to establish and maintain high standards of ethics amongst its members, staff and volunteers. CLAN's ethical principles are:

- Honesty – CLAN acts honestly and truthfully so that public trust is protected and donors and beneficiaries are not misled;
- Respect – CLAN acts with respect for the dignity of our organisation and with respect for the dignity of partners, donors and beneficiaries;
- Integrity – CLAN acts openly and with regard to our responsibility for public trust. We disclose all actual, or potential conflicts of interest and avoid any appearance of ethical, personal or professional misconduct;
- Empathy – CLAN works in a way that promotes our purpose and encourages others to use the same professional standards and engagement. CLAN values individual privacy, freedom of choice, and diversity in all its forms; and
- Transparency – CLAN reports transparently about the work we do, the way donations are managed and disbursed, and cost and expenses in an accurate and clear manner.

Risk & Audit Subcommittee

Joseph Hansen – Chair

Grace Strik – Secretary

Catherine Cole – Member

Veronika Maleš – Member

CLAN's Risk and Audit Subcommittee was established in February 2022, with the role of providing governance, oversight and leadership to ensure efficient, effective and ethical financial management and work related to risk management for CLAN in its work overall and in specific projects as required, as well as ensuring effective due diligence in relation to partnerships and other arrangements involving external parties.

The Subcommittee set out to achieve the following outcomes:

- Develop, monitor and present budget, expense and financial risk management reports
- Develop and maintain a Fraud Control Plan
- Facilitate the annual financial audit
- Develop and maintain financial and risk related policies
- Partner due diligence assessments
- Conduct and assist in the preparation of risk assessments for CLAN and CLAN projects as required
- Maintain the risk management plan and risk register
- Manage the CLAN Constitution, Policy Handbook and Induction Handbook
- Develop training packages for the CLAN Committee, project leads, partners as required
- Collect and collate data for reporting as required
- Projects, research and reports as required.

Over the past financial year, the Risk and Audit Subcommittee has held four meetings. These meetings consist of a regular review of the CLAN and @MATES4Kids Risk Register, financial issues, and an assessment project-related risks and expenses.

Financial Information

The Treasurer reports that CLAN is compliant with the Australian Council for International Development (ACFID) financial policies and requirements, in particular, the Fundraising Policy.

There has been no change in auditor from the prior year, and CLAN's 2022/2023 financial statements have been signed off.

In the 2023 Financial Year, CLAN made a loss of \$4,234. Total donation income came to \$58,365, including grant income of \$41,300, while expenses totalled \$62,599.

Non-discretionary expenses were \$10,531 which was slightly higher than last year, driven by spending on educational resources for various communities including OI and epilepsy.

Discretionary/project expenses were \$52,068, of which, \$12,068 went to CLAN's projects. These projects accomplished the following:

Burundi:

CLAN funded the Burundi NCD Alliance to implement community development initiatives in support of the T1Diabetes Community of Burundi. Club meetings, consultations and educational sessions were delivered.

Mates4Kids:

CLAN has been proud to support the establishment of the @MATES4Kids movement. Funds have supported UN events, development of informational resources and Secretariat functions.

Indonesia:

Funds were shared with Indonesia to support childhood NCD Community activities, such as Wishbone Day celebrations (for the OI Community), Club meetings, translation of Child-Friendly Rights Flyers into Bahasa Indonesia and community consultations.

Sri Lanka:

CAH medicines were exported from Pakistan to Sri Lanka (with funding support from the CAH Community of Germany) in support of the CAH Community of Sri Lanka during their recent financial downturn.

Indigenous NCDs:

The IndigenousNCDs movement was founded by CLAN in 2018, with a view to promoting the voices and perspectives of First Nations peoples in the international NCD discourse. First Nations peoples are now a regular feature in WHO and NCD Alliance activities, and a video on the experiences of Ms LaVerne Bellel (CEO of AMS Redfern) in 2022 was an especial highlight. IndigenousNCDs was closed as a company in 2024 but continues as a social media platform and website.

FY24

From 1 July 2023, CLAN has been running at a profit thanks to generous personal donations.

Upcoming non-discretionary expenses will include auditor fees and insurance, which will come to approximately \$5,500.

CLAN has a current cash balance of \$40,593.

Financial Report - 30 June 2023

CLAN (Caring and Living As Neighbours) Incorporated
ABN 30 897 322 928

CLAN (CARING & LIVING AS NEIGHBOURS) INCORPORATED
COMMITTEES' REPORT

For the year ended 30 June 2023

Your committee members present their report together with the financial statements of CLAN (Caring & Living As Neighbours) Incorporated for the financial year ended 30 June 2023.

Committee members

The names of the committee members in office at anytime during or since the end of the year are:

Dr Kate Armstrong (President)
Catherine Cole (Vice-president)
Joseph Hansen (Treasurer)
Marilyn Hansen
Laura Colenbrander

Principal activities

CLAN is committed to equity for children living with chronic health conditions in resource poor countries.

CLAN's Strategic Framework For Action facilitates multisectoral, collaborative and community development focused efforts on five key pillars:

- Affordable access to essential medicines;
- Education, research and advocacy;
- Optimal medical management;
- Encouragement of Support Groups; and
- Reducing poverty and promoting financial independence.

The majority of CLAN's work occurs in partnership with communities, health professionals and other stakeholders in the Asia Pacific and Africa.

Significant Changes

No significant change in the nature of these activities occurred during the financial year.

Operating Result


The loss after providing for income tax amounted to \$4,234.

Auditor's Independence Declaration

A copy of the auditors independence declaration as required under s60-40 of the Australian Charities and Not-for-profits Commission Act 2012 follows.

Signed in accordance with a resolution of the members of the committee:



Dr Kate Armstrong

Catherine Cole

29 October 2023

CLAN (CARING & LIVING AS NEIGHBOURS) INCORPORATED
STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME
For the year ended 30 June 2023

	Note	2023 \$	2022 \$
Income			
Donations and gifts	2	16,784	25,571
Grants	3	41,300	23,064
Investment Income	4	281	4
		<u>58,365</u>	<u>48,639</u>
Expenses			
International Programs	5	(52,068)	(29,865)
Accountancy & Audit		(2,583)	(2,621)
Bank Charges		(90)	(80)
Consultancy		(2,239)	-
Insurance		(2,917)	(2,831)
Printing, Postage & Stationery		(430)	(277)
Subscriptions		(1,874)	(1,803)
Teleconferences		(398)	(1,443)
Total expenses		<u>(62,599)</u>	<u>(38,920)</u>
Surplus/(deficit) for the year attributable to the members of CLAN (CARING & LIVING AS NEIGHBOURS)		(4,234)	9,719
Other comprehensive income for the year		<u>-</u>	<u>-</u>
Total comprehensive income for the year attributable to the members of CLAN (CARING & LIVING AS NEIGHBOURS)		<u>(4,234)</u>	<u>9,719</u>

The above statement of profit or loss and other comprehensive income should be read in conjunction with the accompanying notes

CLAN (CARING & LIVING AS NEIGHBOURS) INCORPORATED
STATEMENT OF FINANCIAL POSITION
As at 30 June 2023

	Note	2023	2022
		\$	\$
Assets			
Current assets			
Cash on hand	6	28,179	32,407
Trade and other receivables	7	777	783
Total current assets		<u>28,956</u>	<u>33,190</u>
Total assets		<u>28,956</u>	<u>33,190</u>
Liabilities			
Total liabilities		<u>-</u>	<u>-</u>
Net assets		<u>28,956</u>	<u>33,190</u>
Members' funds			
Retained surpluses		<u>28,956</u>	<u>33,190</u>
Total members' funds		<u>28,956</u>	<u>33,190</u>

The above statement of financial position should be read in conjunction with the accompanying notes

CLAN (CARING & LIVING AS NEIGHBOURS) INCORPORATED
STATEMENT OF CHANGES IN EQUITY
For the year ended 30 June 2023

	Retained profits \$	Total members' funds \$
Balance at 1 July 2021	23,471	23,471
Surplus for the year	9,719	9,719
Other comprehensive income for the year	-	-
Total comprehensive income for the year	9,719	9,719
Balance at 30 June 2022	<u>33,190</u>	<u>33,190</u>
	Retained profits \$	Total members' funds \$
Balance at 1 July 2022	33,190	33,190
Deficit for the year	(4,234)	(4,234)
Other comprehensive income for the year	-	-
Total comprehensive income for the year	(4,234)	(4,234)
Balance at 30 June 2023	<u>28,956</u>	<u>28,956</u>

The above statement of changes in equity should be read in conjunction with the accompanying notes

CLAN (CARING & LIVING AS NEIGHBOURS) INCORPORATED
STATEMENT OF CASH FLOWS
For the year ended 30 June 2023

	Note	2023 \$	2022 \$
Cash flows from operating activities			
Receipts from customers		64,208	49,376
Payments to suppliers and employees		(68,436)	(39,702)
Interest received		-	4
Net cash from/(used in) operating activities	9	<u>(4,228)</u>	<u>9,678</u>
Net cash from investing activities		<u>-</u>	<u>-</u>
Net cash from financing activities		<u>-</u>	<u>-</u>
Net increase/(decrease) in cash and cash equivalents		(4,228)	9,678
Cash and cash equivalents at the beginning of the financial year		<u>32,407</u>	<u>22,729</u>
Cash and cash equivalents at the end of the financial year	6	<u><u>28,179</u></u>	<u><u>32,407</u></u>

The above statement of cash flows should be read in conjunction with the accompanying notes

Note 1. Summary of Significant accounting policies

New or amended Accounting Standards and Interpretations adopted

The incorporated association has adopted all of the new or amended Accounting Standards and Interpretations issued by the Australian Accounting Standards Board ('AASB') that are mandatory for the current reporting period.

Any new or amended Accounting Standards or Interpretations that are not yet mandatory have not been early adopted.

Financial Reporting Framework

The committee have prepared the financial statements on the basis that the association is a non-reporting entity because there are no users dependent on general purpose financial statements. These financial statements are therefore special purpose financial statements that have been prepared in order to meet the requirements of the Australian Council of International Development (ACFID) Code of Conduct, the Australian Charities and Not-for-profits Commission Act 2012 (ACNC Act) and the Associations Incorporation Act 2009 New South Wales. The association is a not-for-profit entity for financial reporting purposes under Australian Accounting Standards.

Statement of Compliance

The financial statements have been prepared in accordance with the mandatory Australian Accounting Standards applicable to entities reporting under the ACFID Code of Conduct, the ACNC Act and the Associations Incorporation Act 2009 New South Wales and the significant accounting policies disclosed below, which the committee have determined are appropriate to meet the needs of members. Such accounting policies are consistent with those of previous periods unless stated otherwise.

Basis of preparation

The financial statements have been prepared on a cash basis and are based on historical costs unless otherwise stated in the notes. Material accounting policies adopted in the preparation of these financial statements are presented below and have been consistently applied unless stated otherwise.

The following significant accounting policies, which are consistent with the previous period unless stated otherwise, have been adopted in the preparation of these financial statements.

These financial statements have been prepared in accordance with the the ACFID Code of Conduct, the ACNC Act, the recognition and measurement requirements specified by the Australian Accounting Standards and Interpretations issued by the Australian Accounting Standards Board ('AASB') and the disclosure requirements of AASB 101 'Presentation of Financial Statements', AASB 107 'Statement of Cash Flows', AASB 108 'Accounting Policies, Changes in Accounting Estimates and Errors', AASB 1048 'Interpretation of Standards' and AASB 1054 'Australian Additional Disclosures', as appropriate for not-for profit oriented entities.

Foreign currency translation

The financial statements are presented in Australian dollars, which is CLAN (CARING & LIVING AS NEIGHBOURS)'s functional and presentation currency.

Note 1. Summary of Significant accounting policies (continued)

a) Revenue and Other Income

Non-reciprocal grant revenue is recognised in profit or loss when the association obtains control of the grant and it is probable that the economic benefits gained from the grant will flow to the association and the amount of the grant can be measured reliably.

If conditions are attached to the grant which must be satisfied before it is eligible to receive the contribution, the recognition of the grant as revenue will be deferred until those conditions are satisfied.

Donations, bequests and interest are recognised as revenue when received.

Revenue from the rendering of services is recognised upon the delivery of the service to the customer

All revenue is stated net of the amount of goods and services tax.

(b) Income tax

The Association is exempt from Income Tax.

(c) Cash on Hand

Cash on hand includes cash on hand, deposits held at call with banks, other short-term highly liquid investments with original maturities of three months or less.

Trade and other receivables

Trade receivables are initially recognised at fair value and subsequently measured at amortised cost using the effective interest method, less any allowance for expected credit losses. Trade receivables are generally due for settlement within 30 days.

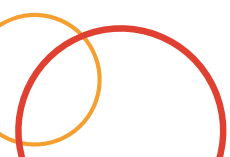
(d) Goods and Services Tax (GST)

Revenues, expenses and assets are recognised net of the amount of GST, except where the amount of GST incurred is not recoverable from the Australian Taxation Office (ATO).

Receivables and payables are stated inclusive of the amount of GST receivable or payable. The net amount of GST recoverable from, or payable to, the ATO is included with other receivables or payables in the statement of financial position.

(e) Comparative Figures

When applicable comparative figures have been adjusted to conform to changes in presentation for the current financial year.



(CLAN (CARING & LIVING AS NEIGHBOURS) INCORPORATED
NOTES TO THE FINANCIAL STATEMENTS
For the year ended 30 June 2023

Note 2. Donations and gifts

	2023 \$	2022 \$
Personal and corporate donations	16,784	25,571

Note 3. Grants

	2023 \$	2022 \$
Diabetes NSW	41,300	23,064

Note 4. Investment Income

	2023 \$	2022 \$
Westpac Interest	281	4

Note 5. International Programs

	2023 \$	2022 \$
Diabetes Projects	40,000	22,295
Burundi	4,340	-
Fiji	-	310
Indigenous NCDs	417	893
Indonesia	730	-
Mates4Kids	2,302	-
Sri Lanka	4,279	-
Uganda	-	1,860
Zimbabwe	-	4,507
	52,068	29,865

Note 6. Current assets - Cash on hand

	2023 \$	2022 \$
CLAN Donations	930	3,776
CLAN Fund	3,053	9,715
CLAN Fund Interest	24,196	18,916
	28,179	32,407

Note 7. Current assets - trade and other receivables

	2023 \$	2022 \$
Other receivables	777	783

(CLAN (CARING & LIVING AS NEIGHBOURS) INCORPORATED)
NOTES TO THE FINANCIAL STATEMENTS
For the year ended 30 June 2023

Note 8. Compliance with ACFID code of conduct

The following financial statements have been prepared in accordance with the requirements set out in the ACFID Code of Conduct. For further information on the code please refer to the ACFID Code of Conduct Guidance Document available at www.acfid.asn.au.

Note 9. Cash flow information

(a) Reconciliation of cash

Cash on hand at the end of financial year as included in the statement of cash flows is reconciled to the related items in the balance sheet as follows:

	2023 \$	2022 \$
Cash at Bank	<u>28,179</u>	<u>32,407</u>

(b) Reconciliation of cash flow from operating activities with net current year profit

	2023 \$	2022 \$
Surplus/(deficit) for the year	(4,234)	9,719
Change in assets and liabilities:		
Decrease/(increase) in trade and other receivables	<u>6</u>	<u>(41)</u>
Net cash from/(used in) operating activities	<u>(4,228)</u>	<u>9,678</u>



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AUDITOR'S INDEPENDENCE DECLARATION UNDER
SECTION 60-40 OF THE AUSTRALIAN CHARITIES AND NOT-FOR-PROFITS COMMISSION ACT 2012
TO THE COMMITTEE OF CLAN (CARING AND LIVING AS NEIGHBOURS) INCORPORATED

In relation to our audit of the financial report of CLAN (Caring And Living As Neighbours) Incorporated for the financial year ended 30 June 2023 an in accordance with the requirements of subdivision 60-C of the Australian Charities and Not-for-profits Commission Act 2012. We declare that, to the best of our knowledge and belief, during the year ended 30 June 2023 there have been no contraventions of:

- i. the auditor independence requirements as set out in the Australian Charities and Not-for-profits Commission Act 2012 in relation to the audit; and
- ii. any applicable code of professional conduct in relation to the audit.

A handwritten signature in black ink, appearing to read 'A. Hardy'.

Allworths Assurance & Advisory Pty Ltd
Level 18, 31 Market Street
Sydney NSW

A handwritten signature in black ink, appearing to read 'Grace Shen'.

Grace Shen
Director
Dated: 29 October 2023

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF CLAN (CARING AND LIVING AS NEIGHBOURS) INCORPORATED

Report on the Financial Report

Qualified Opinion

We have audited the financial report of CLAN (Caring And Living As Neighbours) Incorporated (the Association), which comprises the statement of financial position as at 30 June 2023, the statement of profit or loss and other comprehensive income, the statement of changes in equity and the statement of cash flows for the year then ended, and notes to the financial statements, including a summary of significant accounting policies, and the statement by members of the committee.

In our opinion, except for the effects of the matter described in the *Basis of Qualified Opinion* section of our report, the accompanying financial report of the Association is in accordance with the *Australian Charities and Not-for-profits Commission Act 2012* (the ACNC Act), including:

- a) giving a true and fair view of the Association's financial position as at 30 June 2023 and of its financial performance for the year then ended; and
- b) complying with Australian Accounting Standards to the extent described in Note 1, the ACNC Act, the *Australian Charities and Not-for-profits Commission Regulation 2013* and the *Associations Incorporation Act 2009 New South Wales*.

Basis for Qualified Opinion

As is common for organisation of this type, it is not practicable for CLAN to maintain an effective system of internal control over fund raising activities and donations until their initial entry in the accounting records. Accordingly, as the evidence available to us regarding revenues from these sources was limited, our audit procedures with respect to these sources had to be restricted to the amount recorded in the financial records. We therefore are unable to express an opinion whether these sources of income of association are complete.

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Report section of our report. We are independent of the Association in accordance with the ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110 *Code of Ethics for Professional Accountants* (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our other ethical responsibilities in accordance with the Code.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Emphasis of Matter – Basis of Accounting

We draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared to assist the Association to meet the requirements of the ACNC Act, and the *Associations Incorporation Act 2009 New South Wales*. As a result, the financial report may not be suitable for another purpose. Our opinion is not modified in respect of this matter.

Responsibilities of the Committees for the Financial Report

The committees of the Association are responsible for the preparation of the financial report that gives a true and fair view in accordance with Australian Accounting Standards, the ACNC Act, the *Associations Incorporation Act 2009 New South Wales* and for such internal control as the committees determine is

necessary to enable the preparation of the financial report that gives a true and fair view and is free from material misstatement, whether due to fraud or error.

In preparing the financial report, the committees are responsible for assessing the Association's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the committees either intend to liquidate the Association or to cease operations, or have no realistic alternative but to do so.

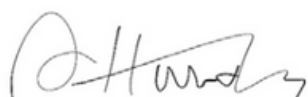
Auditor's Responsibilities for the Audit of the Financial Report

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

As part of an audit in accordance with the Australian Auditing Standards, we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Association's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the committees.
- Conclude on the appropriateness of the committees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Association's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the Association to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial report, including the disclosures, and whether the financial report represents the underlying transactions and events in a manner that achieves fair presentation.

We communicate with the committees regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.



Allworths Assurance & Advisory Pty Ltd
Level 18, 31 Market Street
Sydney NSW



Grace Shen
Director
Dated: 29 October 2023



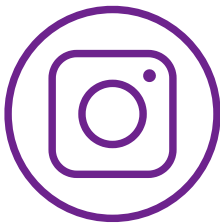
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Caring & Living As Neighbours