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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. HOWEVER, 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 A 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 a 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 as a Deductible Gift Recipient (DGR).

**Our Vision** is that all children living with chronic health conditions in resource-poor settings 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 Innovator 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.

Our model is built around five pillars of action:



1: Access to Medicines and Equipment



2: Education, Research and Advocacy



3: Optimal Medical Management



4: Strong Support Groups



5: Financial Independence

# **COMMITTEE MEMBERS**



DR KATE ARMSTRONG

Founder and President



CATH COLE

Vice President



JOSEPH HANSEN

Treasurer



MARILYN HANSEN

Secretary



STEPHANIE CARDE

**Public Officer** 

# **ABOUT US**

**CLAN's Guiding Principles** inform all of our activities and initiatives. Such values related to CLAN's work include:

- 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.



# PRESIDENT'S REPORT



Every annual report offers an opportunity to reflect on the year that has just passed, and there is no question 2019-20 has been very unique! COVID-19 had changed the world forever, and it's timely to reflect on the impact the pandemic has had on CLAN and the many communities and partners we work with around the world.

At its heart, CLAN is committed to health equity for children living with chronic health conditions in resource poor settings. CLAN is committed to redressing the avoidable and unfair differences in health that exist for children living with Non-Communicable Diseases (NCDs) and other chronic health conditions both within and between populations. It is not acceptable that children in resource poor settings are prevented from achieving their full potential in life because of completely preventable and unjust reasons.

CLAN has learned a lot over the years about the determinants of, and solutions to health inequities for children living with chronic conditions. Our five pillars continue to guide our work, and consistently point us in the direction of key priorities families tell us they need addressed so their children might enjoy the highest quality of life possible. As a small NGO, it is imperative sustainability is at the core of all we do. In recent years CLAN's focus has been on climate-friendly approaches, and has included a commitment to:

- Reducing travel by CLAN's team, with finances saved dedicated to in-country Club and Community events instead
- The use of social media and publications to advocate and promote CLAN's framework, educational resources and community messages
- The role of Community Development Officers in-country
- Grants for young health professionals to facilitate projects in-country with support from local mentors and engagement of Community members
- Promoting Indigenous voices, not just to #BeatNCDs, but also to share wisdom regarding the best ways to care for our planet's health

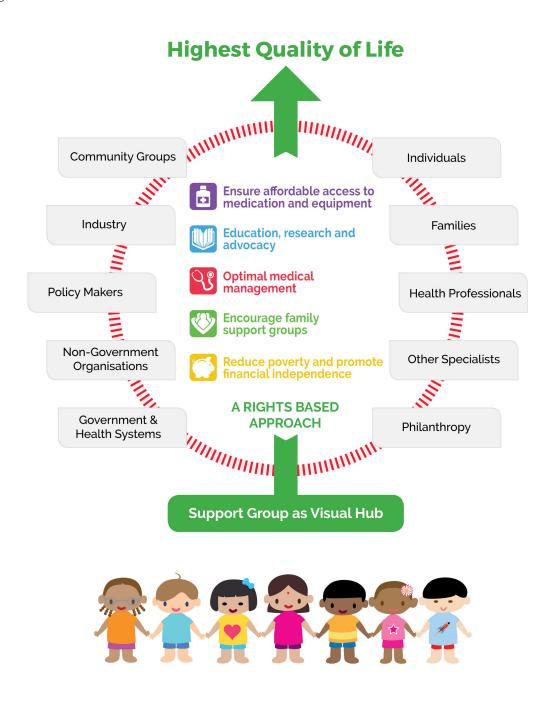
Not surprisingly, these approaches have worked extremely well during the COVID-19 Pandemic, and emphasised the benefits of sound policies. Highlights have included:

- Successful roll-out of CLAN-APPES Grants to support CAH, Diabetes and Thalassaemia Communities in the Asia Pacific region
- Use of social media to promote child-friendly COVID-19 messaging and showcase Indigenous strengths and successes during the pandemic
- Support of Indigenous participation in WHO online events
- Increase in publications, presentations and story-telling

The coming year will present many challenges, and equitable access to COVID vaccines will undoubtedly be a priority for all. As we figure out the best next steps for critical action it's encouraging to look back and be reassured CLAN's strong foundational principles, policies and frameworks have the capacity to guide us safely through even the most difficult times. CLAN is committed to continued collective and collaborative action so we might all emerge from these challenging times stronger, healthier and happier. Thank you to all who have supported CLAN's work over the years, and continue to walk the journey with us. Stay safe and strong.

# 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.





CLAN is proud and honoured to present the Honorary Associate Membership for 2019-2020 to Nadine Clopton. She has been on board as a youth representative with CLAN since July 2016.

Nadine is a recent graduate of Lehigh University in Bethlehem, Pennsylvania in the United States. She has completed a double-major in Public Health and Political Science with a dual minor concentration in Sustainable Development and Environmental Studies.

Through my association with CLAN I had a myriad of incredible experiences and opportunities to dive into advocacy. Following my experience as the first Youth Representative to serve at the UN in Geneva, Switzerland, I attended the World Health Assembly where I had the opportunity to connect in person with many of those who would go on to found the Indigenous NCDs movement as well as to foster connections to key players in the NCD and global health space. I continued this work throughout UNGA and the High-level meeting on NCDs in 2018. Following that, I was invited to work alongside UNICEF in shaping what would become the 40th Anniversary of Alma Ata: Primary Health Care conference held in Astana, Kazakhstan. I ensured that both Indigenous communities and children living with NCDs in developing settings were not left out of the dialogue in the planning process. In September 2018, I was elected to serve as an ex-officio Youth Chair on the NGO DPI Executive Committee at the United Nations, the third student ever to do so. In the spring, I spoke at the Commission on the Status of Women on 3 different panels, highlighting the work of CLAN and the immense disparities in health access and outcomes for the communities we serve, particularly highlighting the challenges imposed on Indigenous communities.

# NADINE CLOPTON



This past summer, I was nominated to run as a fully-fledged Director on the UN NGO Executive Committee and campaigned alongside seasoned NGO Presidents. To my great surprise and overwhelming excitement, I was elected to serve as a Director, the first young person to ever hold this role, and now I serve as the appointed Chair of the Youth and Intergenerational Subcommittee.

In late 2019, myself and a team of youth from every corner of the globe came together and authored the Global Youth Climate Action Declaration which is a comprehensive list of demands geared towards member states from the global community of youth, the first of its kind, with detailed policy implementation suggestions for tackling climate change. This declaration is owned by no one person or organization, yet is owned by all young people around the world. We have thousands of signatories thus far and are conducting ongoing consultations in multiple languages, with affected communities such as climate refugees, and with keepers of environmental wisdom such as Indigenous communities. As a Youth Representative for CLAN, I have played a pivotal role in writing and moving this document forward, as well as ensuring that there is ample consideration of the health impacts of NCDs on children and climate change's role in exacerbating environmental health-related issues infused throughout the text of the document.

Moving forward, I plan to continue serving as a Director on the UN NGO Executive Committee as well as working as a co-organizer in the Global Youth Climate Action Declaration movement. Both of these roles will allow me to enhance the meaningful inclusion of Indigenous communities and serve as a platform for the work of CLAN. Additionally, through my role as Director, I am working tirelessly to create opportunities for young people outside of the NYC area to develop their leadership and advocacy capacities as well as enhance global youth engagement. I envision this as a form of regional leadership structure and I will ensure that there is inclusion of Indigenous youth in this program. I am hoping to reconnect with the young people who have an existing relationship with CLAN and share key opportunities for growth and engagement with them as well as develop new connections to amplify CLAN's work.

CLAN is a prime example of an organization built upon a foundation of equity, opportunity, and empathy. CLAN's work deserves to be shared on the global stage at the UN in New York and the relationship which Lehigh has with CLAN (as well as other NGOs) has allowed CLAN's message and incredible work to spread around the world. I hope that I can continue to contribute to the work and mission of CLAN now and throughout my career.



# IndigenousNCDs

# PROMOTING THE VOICES AND EXPERIENCES OF INDIGENOUS PEOPLES WITHIN THE GLOBAL NON-COMMUNICABLE DISEASES DISCOURSE

Since first engaging in the international Non-Communicable Disease (NCD) discourse in 2010 CLAN has become increasingly concerned about the lack of focus on Indigenous Peoples. There are an estimated 370 million Indigenous Peoples living in 90 countries across the world, and the evidence indicates Indigenous Communities are inequitably burdened by NCDs. Despite this, their voices have been lacking within the international NCD discourse.

In 2018, CLAN consulted with Indigenous Peoples who were interested in engaging within the International NCD discourse. In partnership with Summer May Finlay, a Yorta Yorta woman from Australia, CLAN founded Indigenous NCDs, a global coalition committed to Indigenous control and advocacy to promote the voices and perspectives of Indigenous peoples on issues relating to the prevention and management of NCDs.

# "Raising Indigenous voices to #BuildBackBetter through the WHO's GCM/NCDs webinar"

On 18 June 2020, Indigenous NCDs was proud to have facilitated connections between WHO, Professor James Ward and Dr Mark Wenitong, to ensure #WeAreIndingeous voices from Australia were able to speak first-hand about the incredible successes of Aboriginal and Torres Strait Islander peoples in Australia during the COVID-19 Pandemic. The webinar was titled, 'NCD Voices in the Decade of Action- The value of linking COVID-19 and NCDs to build back better,' and had the goal of acknowledging and showcasing leadership and strengths of Aboriginal people and Communities during COVID-19. The webinar highlighted links between COVID-19, NCDs and mental health conditions, allowing for knowledge sharing, with a strong emphasis on lived experience around the subject matter, ultimately contributing to a better understanding of the interlinkages of the double burden of disease within a global pandemic.



# **IndigenousNCDs**







To date, Indigenous NCDs has focused on bringing the voices and perspectives of Indigenous Peoples to the NCD movement, and have been proud to engage in the following events:

Over the past year, Indigenous NCDs has focused on bringing the voices and perspectives of Indigenous Peoples to the NCD movement, and have been proud to engage in the following events:

World Indigenous Cancer Conference, September 2019, Alberta, Canada In 16-19 September 2019, CLAN facilitated the attendance of Kristine Falzon, a Gymmeah Walbunja Wandiwandian- Gadhu Balaang Saltwater Woman from Australia's South Coast. CLAN was proud to promote Krissy's voice and share her Communities' experiences of NCDs. This was the second time Indigenous Peoples from Civil Society have actively engaged in the global CD discourse. CLAN will furthermore continue to explore such opportunities for engagement. Kristine's experience at this conference are summarised below.

'I had the privilege of being asked to present at the World Indigenous Cancer Conference (WICC) in Canada, the conference theme was "Respect, Reconciliation, and Reciprocity: Connecting Across Knowledge Systems" with presenters from across the world who specialised in First Nations cancer care. the WICC committee approached me and Waminda to speak on behalf of our organisation, community and first nation Australians regarding "Community voices on indigenous cancer pathways: challenges & solutions" as part of Plenary 1. This opportunity became reality with the generous support of the WICC Committee, Cancer Council NSW and CLAN (Caring & Living as Neighbours)/Indigenous NCDs movement.'

Kristine's presentation discussed key successes of Waminda's Comprehensive Care program including:

- 1. Providing Client-led care that ensures informed choice, engagement and participation in their individual health journey;
- 2. Integrated care that adopts a social model of care not privileging bio-medical model;
- 3. Linking culture with education, health and well-being to provide cultural safe and community driven practices while increasing community health literacy awareness;
- 4. Strengthening effective partnerships for comprehensive referral/support pathways across the Aboriginal community controlled, private and public health sectors;
- 5. Providing an Influential robust voice from grass roots community to key peak health bodies;
- 6. Promoting positive messaging that acknowledge strengths-based and trauma-informed care that recognises the impact of colonisation and systematic racism;
- 7. Building capacity within local communities and Aboriginal workforce to promote positive, healthy lifestyle place-based initiative.



# Report on Asia Pacific Pediatric Endocrine Society (APPES) and University of Medicine and Pharmacy (UMP), Ho Chi Minh City, Vietnam

#### PREPARED BY ANGIE MIDDLEHURST

On 5 October, 2019, a combined APPES and UMP Teaching Course was held to provide Updates on Pediatric Endocrinology, and two members of CLAN (Prof Maria Craig and Mrs Angie Middlehurst) were thrilled to visit Vietnam again, and reconnect with colleagues and friends they had worked with previously through CLAN. Participants comprised more than 150 doctors from all over Vietnam, the majority being from the south of the country. Tran Diep Tuan, MD, PhD, Associate Professor of Pediatrics and President of the UMP at Ho Chi Minh City, opened the workshop proceedings. Dr Huynh Thi Vu Quynh, MD, PhD, coordinated the very successful and well –received workshop, with international speakers and Dr Quynh presenting on a variety of topics:

- **Professor Maria Craig:** Medical Management of diabetes, Diagnosis and management of hyperthyroidism in children, Diagnosis and treatment of Growth Hormone Disorders in children
- Associate Professor Jeerunda Santiprabhob (Thailand): Management of common pediatric endocrine emergencies, Congenital hyperinsulinism
- Associate Professor Cindy Ho (Singapore): Diagnosis and treatment of Rickets in children, Late endocrine effects in pediatric cancer survivors
- Dr Huynh Thi Vu Quynh: Update and diagnosis and treatment of CPP
- Mrs Angie Middlehurst: Management of diabetes in children and adolescents practical aspects

CME points and certification of attendance were provided to all participants.

Dr Quynh spent time training in Australia with support from CLAN and Children's Hospital Westmead almost ten years ago, and shared some interesting updates regarding patients now seen at Children's Hospital Two in HCMC. Dr Quynh currently sees approximately 200 children (until age 15 years) who are living with CAH, and the same number (200) with type 1 diabetes.

n recent years, Dr Quynh changed the education program for postgraduate medical students. They are now trained in CAH, diabetes and emergency management of endocrine diseases, so that more patients with CAH and diabetes are now diagnosed early and followed up by doctors in other provinces (not just in Ho Chi Minh City). This saves families money and time in travel.

All at CLAN send heartfelt congratulations to Dr Huynh Thi Vu Quynh, MD, PhD on her recent well-deserved appointment as Vice Head of Pediatric Department, Head of Educational Quality Assurance Unit, Faculty of Medicine - University of Medicine and Pharmacy at HCMC. Dr Quynh has worked tirelessly for the children and families in her care and her hard work is acknowledged and much appreciated.



### **Publications**

#### CLAN WAS PROUD TO CONTRIBUTE TO THE FOLLOWING **PUBLICATIONS**



#### universal health coverage too



WHO first created an Essential Medicines List (EML) for Children (EMLc) in 2007, 30 years after the first EML for adults. Its purpose is to ensure that medicines in the health system are prioritised in an evidence-based manner to meet children's needs. The EMLc is a potentially powerful instrument to ensure that medicines are available, accessible (ie, affordable, physically accessible and with accessible information), acceptable, and of good quality, thus strengthening health equity.

The EML and EMLc are meant to inform WHO Member States' decisions regarding which medicines to prioritise at the national level. Comparison between the WHO EMLc and national EMLs has been used to monitor whether countries are promoting access to paediatric medicines, although few countries publish a list intended for children independently from their national EML.<sup>2</sup>

Each new product added must meet strict evidence based criteria determined by the WHO Expert Committee on the Selection and Use of Essential Medicines.<sup>34</sup> In 2018, WHO released the first edition of the Model List of Essential in-Vitro Diagnostics (EDL). The EDL covers all age groups and recommends laboratory tests for routine patient care and for detection and diagnosis of a wide array of communicable and non-communicable diseases (NCDs). The EDL is intended to complement the EMLs and enhance their impact.

In 2019, WHO published its seventh edition of the EMLc and second edition of the EDL. NCD Child, a global coalition that advocates for the inclusion of children and adolescents through a lifecourse approach in the global NCD agenda, has identified four major areas of action to facilitate implementation of the EMLc and EDL for NCDs: expand NCD scope; broaden the definition of child; improve the lists' utility; and actively support translational activities.

Regarding scope, EMLc has traditionally prioritised medicines for infectious diseases, reflecting their historical preponderance and ongoing burden. A shift towards increased NCD medicine content, such as for cancer, has been seen. However, medicines relevant to other NCDs (including endocrinopathies, mental health conditions, and respiratory diseases) require higher priority than is currently given. A similar shift in the EDL also needs to take place (appendix).

Regarding definition, the EML includes medicines elevant to the whole population, but EMLc highlights therapies only for children up to age 12 years. The needs of adolescents are overlooked, coinciding with a lifecourse period during which many mental health conditions emerge and NCDs might be first diagnosed. Furthermore, at a time when neonatal screening is receiving more attention in low-resource settings, the EDL should include tests specific to neonatal screening for NCDs, such as congenital hypothyroidism or sickle-cell disease

Regarding utility, both EMLc and EDL are published as pdf documents that list medicines (by therapeutic class) and diagnostic tests (by health-care facility level), with minimal notes to explain their possible use. We suggest the EMLc and EDL be integrated and presented in an interactive online format that allows for progressive addition of detailed information and links to evidence based guidelines, as was recently done for infectious diseases and for cancer. This format would further promote the main objective of the EMLc and EDL: to inform governments' decisions about priority medicines and tests at national levels.

Regarding translation, inclusion of medicines and technologies in EMLc does not guarantee affordable and high-quality medicines within countries. Evidencesed and up-to-date national EMLcs are required. Implementation at national and local levels depends on many factors, including: linkage of EMLc to national nt guidelines, other policy and legal frameworks, and health financing and insurance schemes; supply chain management (including cost of paediatric formulations, bioavailability, and stability); and health workforce strengthening through the action of professional societies and public health organisations.5 Universal access to diagnostic testing also requires a supportive health system infrastructure, such as quality-controlled laboratories.

Processes for evidence-based selection, implement ation, and monitoring and evaluation of national EMLs are often lacking.7-9 For children and young people, the need for specialised product formulations further complicates these challenges. Decades of underinvestment in clinical trials to properly license paediatric medicines limits the scope of eligible treatments.<sup>20</sup> Many





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Summer Finlay and Kate Armstrong: Indigenous languages must play a role in tackling noncommunicable diseases

August 13, 2019

In order to improve health outcomes for Indigenous people they must be involved in the creation and implementation of policies, this means a commitment to indigenous languages, say Summer Finlay and Kate Armstrong

According to the UN, Indigenous languages are "at risk of disappearing" prompting the UN General Assembly to declare 2019 the International Year of Indigenous Languages (IYIL). [1] However, the IYIL should be about more than just language revival. It should also be embraced as a platform for promoting and protecting Indigenous peoples' health and wellbeing, specifically regarding the prevention and management of noncommunicable diseases (NCDs).

It is well documented that Indigenous people (estimated to number 370 million in over 90 countries) often have poorer health outcomes than other people within their respective countries with NCDs contributing significantly to the morbidity and mortality of Indigenous people. [2-6] The drivers of health disparity are complex and include social determinants of health; the conditions within which "people live, work and age." [7] The solutions required to address inequalities are equally as complex. Culture should be a constant in the attempt to tackle the unacceptable health disparity for Indigenous peoples.

Indigenous Peoples globally enjoy rich and diverse cultures, but many of these are under threat. Colonisation and globalisation continue to undermine Indigenous peoples' cultures and languages, and create a situation where Indigenous people are very often living in poverty and experiencing poorer health outcomes and higher rates of preventable NCDs than their non-Indigenous counterparts. [8-16]

Finlay, S. and Armstrong, K., 2019. Summer Finlay and Kate Armstrong: Indigenous languages must play a role in tackling noncommunicable diseases - The BMJ. [online] The BMJ. Available at: <a href="https://blogs.bmj.com/bmj/2019/08/13/summer-finlay-and-kate-armstrong-indigenous-">https://blogs.bmj.com/bmj/2019/08/13/summer-finlay-and-kate-armstrong-indigenous-</a> languages-must-play-a-role-in-tackling-noncommunicable-diseases/>

### WHO Global Meeting to Accelerate Progress towards SDG Target 3.4 on Noncommunicable Diseases (NCDs) and Mental Health Report

#### PREPARED BY DR ANDREW TWINEMATSIKO

Noncommunicable diseases (NCDs) - mainly cancer, cardiovascular disease, chronic respiratory diseases, and diabetes - are the most common cause of death and disability worldwide, accounting for 70% of all deaths and more than three out of four years lived with a disability. NCDs (non communicable diseases) are the number 1 cause of death and disability worldwide, and impose years of disability on those affected and their families. NCDs are a significant threat to achieving internationally agreed development goals.

The financial burden of NCDs is immense, and the financial investment to alleviate this burden on patients, families and carers is comparatively small. WHO's Best Buys' offer options that provide not only financial return on investment, but also health and social benefits. Mental health has increasingly become a global burden and its linkage with NCD community in care will improve outcomes. Lack of access and high cost of care, essential medicines and technologies increases morbidity and mortality, and can force people and families into poverty due to disability and out-of-pocket expenses.

#### Global Meeting 2019:

- The WHO Global meeting was health in Muscat capital of Oman at Kempiski Hotel from the 9th to 12th December 2019.
- The meeting was composed of participants from the Ministry of Health NCD departments, WHO HQ and regional offices and civil society organisations. It was organised under 4 key segments.
- Second Global meeting of National NCD and Mental Health Directors and focal points (Mix of strategic policy and technical sessions and restricted to country participants)
- High-level segment with senior speakers from the 6 WHO regions
- Multi-stakeholder partners forum, including the active participation of WHO Collaborating Centres, non-State actors in official relations with WHO and members of the UN Inter-Agency Task Force on NCDDs and the WHO Global Coordination Mechanism on NCDs
- Regional meetings, side events and local site visits

It had speakers from all the 6 WHO regions, youth, people living with NCDs and mental health as well as civil society. We were lucky that our President, was among the great speakers at the meeting.

#### **Youth Meeting:**

We had 2 successful youth meetings with other young participants, shared a lot on our works and opportunities for more youth engagement. We are currently working on an outcome document that will be shared upon completion.

#### Meeting:

I attended several meetings and break out sessions over the 3 days, with a lot of learning and interacting with several other participants, though had no speaking role but the ideas shared all over the meeting sessions are important

for my work back home.



### WHO Global Meeting to Accelerate Progress towards SDG Target 3.4 on Noncommunicable Diseases (NCDs) and Mental Health Report



#### **Engagements:**

I was privileged to meet several leaders in the NCD and mental health sector, exchanged contacts and shared about the work we do. Thanks to Dr. Kate for the introductions on many, I have since followed up on some of the people met and yet to visit especially our Commissioner for Uganda.

#### Site Visit:

I participated in the site visits, key accomplishments was learning about the health care system in Oman compared to one in our country, there were several differences in terms of organisation and opportunities for learning.

#### **Challenges:**

- Had very few young people as participants (25 out of all participants)
- Youth did not have speaking role in many of the sessions
- Less time for the sessions hence less interaction between speakers and participants.

#### **Action Way Forward:**

- Follow up with mails for the contacts I gathered during the meeting.
- Share knowledge I received with my team back home.
- Finalise the youth action document following the meeting.
- Continue engaging more members in the network on social media especially twitter.
- Lobby for participation of young people and people living with NCDs and mental health in future events regarding NCDs.

#### **Acknowledgement:**

- With special thanks, I would like to expend my gratitude to Caring and Living As Neighbours (CLAN)
  especially Dr. Kate Armstrong for the mentorship, financial support, recommendation and promoting
  my work and great support rendered during the meeting.
- Special thanks to WHO, Oman government for organising the event.
- The entire Youth participants at the Forum for the coordination and getting the Call to Action ready.



# **Updates from Uganda**

# DELIVERY OF ANTI-EPILEPTIC MEDICINES TO SUPPORT GROUP MEMBERS AMIDST COVID-19

Access to medicines has always been a challenge to communities in Uganda, even prior to COVID-19, with key barriers including distance from families to health facilities, cost of medicines, stock outs of medicines and equipment and chronically under-funded health systems. In recent years, with support from the Australian non-government organisation CLAN (Caring & Living As Neighbours), our team of volunteers established support groups in Uganda for children and young people living with Nodding Syndrome and Epilepsy. Using CLAN's strategic framework for action we have committed to establishing innovative approaches to improving quality of life for children in these communities, with specific focus on improving access to essential medicines and equipment (the first of CLAN's five pillars).

The COVID-19 Pandemic has exacerbated existing inequities and access gaps globally. During the pandemic many families we work with have been asking for medicines to be delivered to their homes given the limited public transport options. Uganda instituted a Country Lock down early in the pandemic, and the consequent ban on private and public transport continues to make it hard for citizens to access hospitals, with only ambulances allowed to operate.

With support from volunteers, our team has developed an innovative response to support group members' calls requesting medicines to be delivered to their homes. An on-call volunteer picks up the medicines from the hospitals that clients are attached to (using their official Patient numbers), and transports the medicines to the clients' home by motor bike at no cost. The logistics of the operations are catered for by the volunteers, and special care is taken to ensure infection control precautions are maintained. The motor bike rider uses appropriate PPE (Personal Protective Equipment) and hand washing sanitisers to ensure both volunteers and clients are protected at all times from COVID-19 infection.

This essential medicine delivery system has been greatly appreciated by support group members and helped to reduce the gap in access to medicines. Looking forward, we plan to explore opportunities and funds to create a mobile application to assist clients even beyond our support groups with requests for essential medicines to be delivered to their homes, with especial focus on other key paediatric populations.





# **International Epilepsy Day**

#### "EPILEPSY - A PUBLIC HEALTH PRIORITY" 10 FEBRUARY 2020

#### PROJECT REPORT BY DR ANDREW TWINEAMATSIKO

This inaugural meeting was a coming together of People Living With (PLW) Epilepsy and Civil Society Organisations (CSOs) working to support PLW Epilepsy in Uganda – especially those helping people cope with the mental health impact of the condition. The event aimed to help everyone get information on what is being achieved by different stakeholders and identify what still needs to be done. We acknowledged that Ugandans are living with a number of epidemics that affect our mental health, and the impact of these can linger on even after a cure is found. Ideally, many organisations will come together to achieve long-term solutions that include both pre- and post-acute care in their work plans, however at times it seems few organisations are willing to help, while others want to help but are unsure how to get involved.

#### Why focus on epilepsy in Uganda?

Epilepsy is a chronic neurologic disorder characterised by recurring seizures, it is one of the leading brain disorders in developing countries. Seizures are brief episodes of involuntary movement that may involve one part of the brain (partial) or all areas of the brain (generalised). Seizure episodes are a result of excessive discharges in the brain and manifest as jerking movements, convulsions, and loss of consciousness to mention. According to WHO, about 50 million people live with epilepsy globally with nearly 2.4 million cases every year. It is estimated that over 80% of people affected by epilepsy reside in Africa, with majority being from low income countries. Uganda is a developing country with an estimated population of over 40 million people, though no recent data about the prevalence and incidence of epilepsy in Uganda, it is estimated that about 400,000 people are living with epilepsy in Uganda accounting for about 1/100 Ugandans. It affects more children than adults

#### **Epilepsy Community in Uganda**

Epilepsy Community Uganda is a project supported by Caring and Living As Neighbours (CLAN), an Australian based NGO. With technical and financial support extended to Uganda, and Volunteers from Patriotic Medics Uganda. Remarks were given by Ms Judith Ainomugisha, she gave the background of the project using the five pillars as extracted under CLAN implementation model. She noted that these pillars will be implemented if we are to realise the goals of the project and improving the quality of life for persons with Epilepsy.

In conclusion, she informed participants that this approach was used for the Nodding syndrome community in Uganda and created a positive impact on the members of the support group. Urged members to work together towards implementation of the model.

She also stressed a point of need to partner with schools that have persons with epilepsy to follow up on their performance, what needs to be done and the challenges that have marked low education levels for PWEs.







# **International Epilepsy Day**

#### Testimonies from persons living with epilepsy

A mother to a child living with epilepsy explained in between tears how it has difficult to cope with life with her child of multiple disabilities. She almost committed suicide due to

harassments from family members, relatives and neighbours who accused her of being a witch or perhaps having committed a big sin thus her child suffering the consequences. She however thanked us for bringing an initiative of support groups and is positive that their meetings will help reduce on the psychological burden of living/caring for persons with epilepsy. A 21-year-old man living with epilepsy told the audience how living with epilepsy looked like an ending dark tunnel but with help from organisations he was able to build confidence and started to believe that epilepsy is neither inability nor a curse. He has been able to complete his studies and is hopeful the support group established will be used to build hope for all PWEs, as the leader of the group, he noted key concerns that organisations and Ministry if Health needs to address and these include:

- Reducing stigma to PWEs
- Ensure access to medicines and reduce drug stock outs
- Increase education on epilepsy especially to schools and support school going children with epilepsy
- Urged organisations to create vocational trainings for those who couldn't continue with school because of epilepsy
- Meaningful involvement in creating epilepsy programs

Another victim explained how his seizures reduced after going through counselling and taking medication regularly. Before being helped by ministry of health he was living in hiding and wasn't participating in anything as people surrounding him believed he was un able of doing anything due to his repeated seizures. He was so grateful to ministry of health for giving a platform to get exposed and getting into different training which have enabled him determine his potential as a person living with epilepsy.

#### **Remarks from Ministry of Health**

Madam Hafsa on behalf of ministry of health showed how everyone has a different misconception on epilepsy. Some think it's caused by evil, others think its form of punishment for wrong doing and other categories think mothers could have done weird things during pregnancy. Therefore, organisations dealing with epilepsy need to channel works mostly in Madam Hafsa on behalf of ministry of health showed how everyone has a different misconception on epilepsy. Some think it's caused by evil, others think its form of punishment for wrong doing and other categories think mothers could have done weird things during pregnancy. Therefore, organisations dealing with epilepsy need to channel works mostly in changing mindsets of people which could also help in eliminating stigma faced by PWE. There's a need to take epilepsy as a priority and major concern in Uganda. Ministry of health calls upon all organisation and individual partners of epilepsy to cooperate in sensitising the masses and ensuring regular supply of drugs. VHTs also need trained on how to handle PWE emotions and to also be able to train the patients on how to handle their emotional changes and symptoms that surface before seizures. She also called upon global fund and CSOs to think on how to solicit funds for the epilepsy epidemic after sharing on how PWE epilepsy are raped with no one to advocate for their rights, some are even divorced for no reason and most of them have been unsuccessful in relationships simply because of their partner's misconception on epilepsy. The whole world needs to appreciate that epilepsy is a disease just like any other.



# **APPES-CLAN Grant Projects**



























In December 2019 CLAN invited APPES Fellows to apply for modest community development grants (up to \$5,000 depending on the activities proposed), to lead projects that drive collaborative action by local paediatric endocrine communities, senior paediatric endocrinologists (as mentors, either in their own country or supporting neighbouring countries) and other stakeholders, with a focus on local priorities that will drive sustainable change to improve the lives of children living with endocrine conditions in resource poor communities.

Three grants were given for projects that could be developed over a 6-12 month period. The strategic focus on young doctors as project leads seeks to invest in the next generation of paediatric endocrinologists of the Asia Pacific region, and actively engage the future champions of Paediatric Endocrinology in efforts to strengthen the capacity of paediatric endocrine communities across the Asia-Pacific region so together we can continue to sustainably drive real change for the children. Projects leads have committed to submit abstracts on their project's achievements at the next APPES Conference in 2021 and this will help all countries learn from one another.

All three projects were off to a flying start at the beginning of 2020, however all three have understandably been impacted by COVID-19 to varying degrees. In some cases this unprecedented situation inspired innovative thinking and new opportunities have already been identified for health professionals, children and their families living with non communicable disease (NCDs) as a result.



# India

#### Dr Koushik Ural H.



Endocrine complication are important causes for morbidity and mortality in children with transfusion dependent Thalassaemia Major. In the second half of 20th century with advent of chelation therapy life expectancy and quality of life of these children improved dramatically. However because of high cost and limited availability, the extent of chelation achieved in the Indian setting is far from acceptable level. For the same reason, they are likely to develop endocrine deficiencies in early life with severe manifestations.

Sexual maturity and gonadal functions are markedly affected by iron toxicity. Hypogonadism can be primary or secondary or combined. Failure to begin puberty may be present in up to 50-100 % patients. Direct free radical

mediated toxicity of anterior pituitary cells and gonads, impaired leptin synthesis have been implicated in pathogenesis (1). Delayed / arrested puberty negatively impacts stature, bone health, psycho social wellbeing. In overburdened system pubertal problems of these children are hardly addressed, which in turn affects quality of life.

Short stature is prevalent in about 50 % of children thalassaemia, especially those after 10 years of age. This can be attributed to chronic anaemia, desferrioxamine toxicity, delayed puberty, growth hormone deficiency and IGF 1/IGF BP3 deficiency. (1)(2) Growth hormone therapy is out of reach to our children, due to the prohibitive cost; resources are usually saved for life-saving transfusion and chelation.

Depending on the extent of chelation, the prevalence of hypoparathyroidism may vary between 3-22 %. However sub clinical hypoparathyroidism may virtually exist in all as age advances.(3)(4) Acute severe hypocalcaemia may cause seizure, tetany, cardiac failure leading to morbidity and mortality. In the long run it thoroughly affects quality of life. Similarly, based on the extent of iron overload, the resulting lipid peroxidation, free radical mediated injury and oxidative stress can result in primary hypothyroidism. Prevalence ranges up to 5-17 %. (5)(6)

With improved life expectancy incidence of exocrine and endocrine pancreatic insufficiency is increasing especially third decade onwards. Though frank diabetes is less common, when combined with impaired glucose tolerance up to 6-14 % of children have glucose metabolism problems.

Adrenal insufficiency is also a less common endocrine problem in children with thalassemia. Mostly manifest as altered diurnal ACTH rhythm or decreased adrenal reserve in later life.(1) However in poorly chelated young children adrenal insufficiency is been reported as early as 5 years. So, in our setting, if not actively looked for, morbidity - mortality caused by adrenal insufficiency may prove costly.

In our setting, because of lack of government support, palliative transfusion and chelation to the extent possible have been the priority. Through this study we can uncover, educate and sensitise health care providers and parents about the burden of endocrine problem and the need for routine screening. As a research tool this study aims at uncovering endocrine abnormalities at an early age, as our children are under chelated and may need early screening. Screening will reduce the economic burden by early treatment of endocrine complications. We hereby express our commitment to conduct the process ethically, satisfying the pillars of CLAN's strategic alignment in an effort to contribute to the care of children with chronic endocrine problems.



# Pakistan

#### Dr Hassana Nadeem

#### **Project Summary**

This research is planned by the paediatric endocrinology department of National Institute of Child Health, Karachi Pakistan, a public sector tertiary care health facility that provide care without any cost. In dealing with patients with adrenal hyperplasia, availability of medicine is a huge challenge as the medicines are neither easily available nor affordable. The families we cater often come from far flung areas to seek treatment. Coming for follow up especially to obtain medications is a real problem to their poor resources as most of them work on daily wages, a day off means loss of revenue for the entire family. This leads to meager follow up, poor medicine compliance and at the end poor control of these children. In order to address all these issues, we design our project to deliver the medication at the patient's door step using courier service. It will save the time and inconvenience of caretaker/guardian. Moreover, it will help in compliance with medicines and then proper follow up in outpatient department. So, our project will help us in better management.

#### **Aim**

To deliver medications of CAH patients at their door step so that we can reduce the burden of visiting parents for medicine each time. It will also improve medication compliance and strengthen the medication persistence.

#### Updates as of June 2020

- Paediatrician's survey
  - Questionnaire has been established
  - Ethical clearance is currently pending due to work activities restrictions and current policies of Ethical Committee in our hospital that prioritise COVID-19-related proposals and result to longer process of our ethical clearance (estimated: more than 6-8 weeks).
- Materials/tools for diabetes education
  - Family-based education sessions will be done after CoVID-19 pandemic is over and after all educational tools are finished
  - Conducted 2 zoom meetings and intense discussion in WhatsApp group during past 2 months with team (layout designer and content editor)
  - Designs of several tools is already finished, others are ongoing
  - Down-payment for design team has been deducted from budget/account
  - Examples of finalised designs are below:
    - Diary/journal design for personal daily notes regarding carb counting,
    - insulin, and BG measurements (to be used by patients with TID)
- Incorporate educational tools into existing mobile app
  - Preliminary meeting with person-in-charge for mobile application team (from Indonesian Pediatric Society) has been conducted in early March 2020, discussing about the possibility of the project à promising results
  - Follow-up meetings are postponed due to CoVID pandemic





















# Indonesia

#### Dr Ghaisani Fadiana

#### **Project Summary**

Management of type 1 diabetes (TID) is still becoming major challenge in Indonesia. There are still many children and adolescents with TID were diagnosed with diabetic ketoacidosis (DKA) at presentation. Real incidence in population is unknown; data regarding complications are unavailable.

There are many factors, which are thought to be contributing to the challenges, such as:

- Lack of awareness of public, government (national and local), and practitioners about the importance of TID, its principal management, and how complications prevention will decrease disease-related death as part of non-communicable diseases (NCDs).
- Lack of adequate insulin distribution to primary and secondary healthcare facilities due to policy, socioeconomic, and geographical characteristics of Indonesia.
- Limitation of insulin prescription for TID patients by national insurance regulation. TID patients could only be prescribed insulin for one month, requiring them to visit hospital every month (with complexity of referral system, financial consequences such as more expenses, long queuing in outpatient clinic, etc)
- Hesitancy from practitioners to use insulin due to lack of knowledge about insulin initiation, fear of insulin complications (e.g. hypoglycaemia, etc).
- Lack of knowledge of patients and families about TID management, which lead to lower compliance and higher risk of complications.

As paediatrician, it is important to take action not only in clinical settings, but also in community level. Therefore, we plan to organise project targeting not only paediatricians themselves as care providers, but also patients and families. We expect that the projects would be inline with CLAN's pillars, such as affordable access to medication and medical equipment; education, research, and advocacy; optimisation of medical management.

Well-established patient support group, as one of our strengths, will be also actively involved both as participants and as collaborators. Involvement of community members will serve as trigger for bottom-up change-making process to improve quality of TID management nationwide. We also expect that these projects could be great examples for other local organisations on how to collaborate with both care providers and patients for better care of TID in children and adolescents in Asia Pacific Region. We have also had existing mobile health app, which are valuable both for paediatricians and patients, particularly in screening, monitoring, education, etc. We believe that developing technology in health, particularly in strengthening national registry and educational platform for patients and families would be a great investment for future child health, especially in TID care and management.

#### Aim

This project aims to improve overall quality of TID care management by involving all important stakeholders, such as paediatricians (by assessing current knowledge, attitude, and behaviour towards. existing TID management; reducing their hesitancy to start insulin therapy for those are indicated; identifying modifiable barriers related to insulin initiation; improving their practices in managing TID) and patients and families (by performing education using newly established educational materials, group based session with families), through optimising current existing mobile health app as educational platform and integrating national registry system into existing mobile PRIMA Apps (which are now used by majority of paediatricians and families).



# **Governance Framework**

#### **ACCOUNTABILITES**

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.

# CLAN (CARING AND LIVING AS NEIGHBOURS) INCORPORATED

ABN 30 897 322 928

#### FINANCIAL REPORT

FOR THE YEAR ENDED 30 JUNE 2020

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#### COMMITTEE'S REPORT

Your committee members submit the financial report of CLAN (Caring And Living As Neighbours) Incorporated for the financial year ended 30 June 2020.

#### **Committee Members**

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

Dr Kate Armstrong Catherine Cole Joseph Hansen Marilyn Hansen Stephanie Carde (appointed 15 December 2019) Julia Ridulfo (Retired 15 December 2019)

#### **Principal Activities**

The principal activities of the association during the financial year were:

a charitable organisation committed to enhancing equitable health outcomes for children living with chronic health conditions in resource poor settings.

#### 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 \$17,852.

#### Auditor's Independence Declaration

A copy of the auditors independence declaration as required under s60-40 of the Australian Charities and Notfor-profits Commission Act 2012 follows.

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

Dr Kate Armstrong

Catherine Cole

10 December 2020

#### 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 accordance with Subdivision 60-C of the Australian Charities and Not-for-profits Commission Act 2012, I am pleased to provide the following declaration of independence to the directors of CLAN (Caring And Living As Neighbours) Incorporated. As the lead audit partner for the audit of the financial report of CLAN (Caring And Living As Neighbours) Incorporated for the year ended 30 June 2020, I declare that, to the best of my knowledge and belief, there have been no contraventions of:

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

McGregor & McGregor Chartered Accountants 591 Hunter Street NEWCASTLE, NSW, 2300

PARTNER: W.I. RINKIN

NEWCASTLE

10 December 2020

#### INCOME STATEMENT

#### FOR THE YEAR ENDED 30 JUNE 2020

	2020	2019 \$
	*	*
INCOME		
Donations and gifts: Monetary		
- Corporate donations	6,000.00	
- Personal donations	1,550.00	6,600.00
Non-monetary	-,000.00	-
Bequests and legacies		
Grants:		
Department of Foreign Affairs & Trade		-
Other Australian Grants		
- Diabetes NSW	54,157.82	22,837.59
Overseas Grants	-	-
Commercial Activites Income		-
Investment Income:		
- Westpac interest	55.15	211.95
Other Income:		
- Members subscriptions	200.00	150.00
<ul> <li>APPES Fundraiser for APPES-CLAN Equity Working Group</li> </ul>		-
Revenue for International Political or Religious Adherence Promotion		
Programs		
TOTAL REVENUE	61,962.97	29,799.54
EXPENDITURE		
International Aid and Development Programs Expenditure:		
International Programs		
Funds to International Programs	E0 400 E0	40 000 07
- Diabetes Projects - Pakistan	52,482.52 5.105.00	48,880.87
- Uganda		2 000 00
- Indonesia	5,539.20	3,000.00
- Indonesia Program Support Costs	5,010.00	-
- Community Development Pakistan		1,108.46
- Community Development Pakistan	-	604.50
Community Education		004.00
- Indigenous NCDs	2,500.00	3,000.00
Fund Raising Costs	2,000.00	3,000.00
- Public	_	
- Government, multilateral and private	_	-
coronina, management and private		

The accompanying notes form part of these financial statements.

#### INCOME STATEMENT

#### FOR THE YEAR ENDED 30 JUNE 2020

	Note	2020 \$	2019
Accountability and Administration - Accountancy & Audit - Bank charges - Consultancy - Insurance - Membership - Subscriptions - Teleconferences Non-monetary expenditure		2,350.00 80.00 1,935.00 2,663.11 - 1,750.00 400.08	2,300.00 181.76 1,000.00 2,643.61 117.79 1,726.00 394.03
Total International Aid and Development Programs Expenditure		79,814.91	64,957.02
International Political or Religious Adherence Promotion Programs Expenditure Domestic Program Expenditure Commercial Activities Expenditure Other Expenditure  TOTAL EXPENDITURE  NET OPERATING SURPLUS (LOSS)		79,814.91 (17,851.94)	64,957.02 (35,157.48)
Other comprehensive income:			
Total other comprehensive income for the year			
Total comprehensive income (expense) for the year  Total comprehensive income (expense) attributable to members of		(17,851.94)	(35,157.48)
the entity		(17,851.94)	(35,157.48)

The accompanying notes form part of these financial statements.

#### **BALANCE SHEET**

#### **AS AT 30 JUNE 2020**

	Note	2020 \$	2019 \$
ASSETS			
CURRENT ASSETS  Cash and cash equivalents  Trade and other receivables  Financial assets	2 3	33,769.39 711.25	51,331.34 1,001.24
Inventories on hand Non-current assets held for sale Other current assets			-
TOTAL CURRENT A	_	34,480.64	52,332.58
NON-CURRENT ASSETS Trade and other receivables Financial assets Non-current assets held for sale Property, plant and equipment	-	-	- - - - -
Investment property		-	-
Intangible assets Other non-current assets			
TOTAL NON-CURRENT ASSETS		-	-
TOTAL ASSETS	_	34,480.64	52,332.58
LIABILITIES CURRENT LIABILITIES Trade and other payables Borrowings Current tax liabilities		:	
Other financial liabilities Provisions Other	_	:	-
TOTAL CURRENT LIABILITIES			
NON-CURRENT LIABILITIES Borrowings		-	-
Other financial liabilities Provisions		-	
Other	-		
TOTAL NON-CURRENT LIABILITIES	-		
TOTAL LIABILITIES	-		50 222 59
NET ASSETS		34,480.64	52,332.58
MEMBERS' FUNDS		_	_
Reserves Retained earnings	_	34,480.64	52,332.58
TOTAL MEMBERS' FUNDS		34,480.64	52,332.58

The accompanying notes form part of these financial statements.

#### STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDED 30 JUNE 2020

	Retained Earnings \$	Total \$
Balance at 1 July 2018	87,490.06	87,490.06
Comprehensive income		
Surplus (loss) for the year	(35,157.48)	(35,157.48)
Total comprehensive income for the year attributable to members of the		
association	(35,157.48)	(35,157.48)
Balance at 30 June 2019	52,332.58	52,332.58
Balance at 1 July 2019 Comprehensive income	52,332.58	52,332.58
Surplus (loss) for the year	(17,851.94)	(17,851.94)
Total comprehensive income for the year attributable to members of the		
association	(17,851.94)	(17,851.94)
Balance at 30 June 2020	34,480.64	34,480.64

### CLAN (CARING AND LIVING AS NEIGHBOURS) INCORPORATED ABN 30 897 322 928

#### STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 30 JUNE 2020

	Note	2020 \$	2019 \$
Cash flows from operating activities			
Receipts from customers		61,907.82	29,587.59
Payments to suppliers and employees		(79,524.92)	(65,209.07)
Interest received		55.15	211.95
Net cash provided by (used in) operating activities	8	(17,561.95)	(35,409.53)
Net increase (decrease) in cash held		(17,561.95)	(35,409.53)
Cash on hand at beginning of financial year		51,331.34	86,740.87
Cash on hand at end of financial year	8	33,769.39	51,331.34

#### NOTES TO THE FINANCIAL STATEMENTS

#### FOR THE YEAR ENDED 30 JUNE 2020

#### 1. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

#### 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 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.

The financial statements have been prepared in accordance with the mandatory Australian Accounting Standards applicable to entities reporting under the Australian Council of International Development (ACFID) Code of Conduct, the Australian Charities and Not-for-profits Commission Act 2012 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.

#### Statement of Compliance

The financial statements have been prepared in accordance with the mandatory Australian Accounting Standards applicable to entities reporting under the Australian Council of International Development (ACFID) Code of Conduct, the Australian Charities and Not-for-profits Commission Act 2012, the Associations Incorporation Act 2009 New South Wales, the basis of accounting specified by all Australian Accounting Standards and Interpretations, and the disclosure requirements of Accounting Standards AASB 101: Presentation of Financial Statements, AASB 107: Cash Flow Statements, AASB 108: Accounting Policies, Changes in Accounting Estimates and Errors, AASB 1031: Materiality and AASB 1054; Australian Additional Disclosures.

#### Basis of Preparation

The financial statements, except for the cash flow information, have been prepared on an accrual 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.

#### (a) Income Tax

The Association is exempt from Income Tax.

#### (b) 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.

#### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2020

#### (c) 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 cf goods and services tax.

#### (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.

#### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2020

		2020 \$	2019 \$
2.	CASH AND CASH EQUIVALENTS  CLAN Donations  CLAN Fund  CLAN Fund Interest	2,577.95 1,687.06 29,504.38 33,769.39	730.74 427.92 50,172.68 51,331.34
3.	TRADE AND OTHER RECEIVABLES  CURRENT Other receivables	711.25	1,001.24
4.	PROPERTY, PLANT AND EQUIPMENT  Plant and equipment Less accumulated depreciation  Total property, plant and equipment	<u>:</u>	6,648.62 (6,648.62)

#### COVID - 19

During the financial year there have been considerable economic impacts in Australia and globally arising from the Coronavirus (COVID-19) pandemic, and Government actions to reduce the spread of the virus.

At the date of signing the financial statements, the Committee are unable to determine what financial effects the outbreak of the virus could have on the association in the coming financial period.

Any financial effects arising from the economic impacts of the virus have been included in the financial statements for the year ended 30 June 2020. The Committee acknowledge their responsibility to continuously monitor the situation and evaluate this impact including whether the association remains a going concern and its ability to pay its liabilities as and when they fall due.

#### 6. EVENTS AFTER THE REPORTING PERIOD

No matters or circumstances have arisen since the end of the financial year which significantly affected or may significantly affect the operations of the association, the results of those operations or the state of affairs of the association in future financial years that are not disclosed elsewhere.

#### COMPLIANCE WITH ACFID CODE OF CONDUCT

The following financial statements have been prepared in accordance with the requirementsset 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.

#### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2020

	2020 \$	2019 \$
8. CASH FLOW INFORMATION		
(a) Reconciliation of cash Cash on hand at the end of financial year as include statement of cash flows is reconciled to the related balance sheet as follows:		
Cash at Bank	33,769.39	51,331.34
	33,769.39	51,331.34
(b) Reconciliation of cash flow from operating activ	ities with net current year profit	
Current year profit after income tax	(17,851.94)	(35,157.48)
Changes in assets and liabilities: (Increase)/decrease in trade & other receivables		
	289.99	(252.05)
Net cash provided by (used in) operating activiti	es (17,561.95)	(35,409.53)

#### STATEMENT BY MEMBERS OF THE COMMITTEE

The committee has determined that the association is not a reporting entity and that this special purpose financial report should be prepared in accordance with the accounting policies outlined in Note 1 to the financial statements.

In accordance with a resolution of the committee of CLAN (Caring And Living As Neighbours) Incorporated, the members of the committee declare that the financial statements as set out on pages 4 to 12:

- 1. present a true and fair view of the financial position of CLAN (Caring And Living As Neighbours) Incorporated as at 30 June 2020 and its performance for the year ended on that date in accordance with the accounting policies described in Note 1 to the financial statements and the requirements of the the Australian Council of International Development (ACFID) Code of Conduct, the Australian Charities and Not-for-profits Commission Act 2012 and the Associations Incorporation Act 2009 New South Wales; and
- at the date of this statement there are reasonable grounds to believe that CLAN (Caring And Living As Neighbours) Incorporated will be able to pay its debts as and when they fall due.
- signed in accordance with subsection 60.15(2) of the Australian Charities and Not-for-profits Commission Regulation 2013.

This statement is signed for and on behalf of the committee by:

President

Dr Kate Armstrong

Vice President

Catherine Cole

10 December 2020

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

#### Report on the Audit of the Financial Report

#### Qualified Opinion

We have audited the financial report of CLAN (Caring And Living As Neighbours) Incorporated (the association), which comprises the committee's report, balance sheet as at 30 June 2020 and the income statement, statement of changes in equity and statement of cash flows for the year then ended, and notes to the financial statements, including a summary of significant accounting policies and 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 CLAN (Caring And Living As Neighbours) Incorporated has been prepared in accordance with the Australian Council of International Development (ACFID) Code of Conduct, Div 60 of the Australian Charities and Not-for-profits Commission Act 2012 (ACNC Act) and the Associations Incorporation Act 2009 New South Wales including:

- (i) giving a true and fair view of the association's financial position as at 30 June 2020 and of its financial performance for the year then ended; and
- (ii) complying with Australian Accounting Standards to the extent described in Note 1, the Australian Council of International Development (ACFID) Code of Conduct, Div 60 of the Australian Charities and Not-for-profits Commission Regulation 2013, and the Associations Incorporation Act 2009 New South Wales.

#### **Basis of Qualified Opinion**

As is common for organisations of this type, it is not practicable for CLAN (Caring and Living as Neighbours) Incorporated 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 amounts recorded in the financial records. We therefore are unable to express an opinion whether these sources of income of the 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 Associations Incorporation Act 2009 New South Wales, the Australian Council of International Development (ACFID) Code of Conduct, the Australian Charities and Not-for-profits Commission Act 2012 and 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 CLAN (Caring and Living as Neighbours) Incorporated 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 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.

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

#### Responsibilities of the Committee for the Financial Report

The committee of CLAN (Caring And Living As Neighbours) Incorporated is responsible for the preparation and fair presentation of the financial report in accordance with the financial reporting requirements of the the Australian Council of International Development (ACFID) Code of Conduct, the Australian Charities and Not-for-profits Commission Act 2012 and the Associations Incorporation Act 2009 New South Wales and for such internal control as the committee determines is necessary to enable the preparation and fair presentation of a financial report that is free of material misstatement, whether due to fraud or error.

In preparing the financial report, the committee is responsible for assessing the association's ability to continue as a going concern, disclosing, as applicable, matters relating to going concern and using the going concern basis of accounting unless the committee either intends to liquidate the association or to cease operations, or has no realistic alternative but to do so.

#### Auditor's Responsibility 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 the 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 committee.
- Conclude on the appropriateness of the committee's 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.

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

We communicate with the committee 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.

McGregor & McGregor Chartered Accountants 591 Hunter Street NEWCASTLE, NSW, 2300

PARTNER: W.I. RINKIN

**NEWCASTLE** 

3 December 2020

### CLAN (CARING AND LIVING AS NEIGHBOURS) INCORPORATED ABN 30 897 322 928

#### CERTIFICATE BY MEMBERS OF THE COMMITTEE

I, Dr Kate Armstrong of Eastwood, NSW and I, Catherine Cole of Sylvania Waters, NSW, certify that:

- We attended the annual general meeting of the association held on 10th December, 2020.
- b. The financial statements for the year ended 30th June, 2020 were submitted to the members of the association at its annual general meeting.

Dated: 10 December 2020

President

Dr Kate Armstrong

Vice President

Catherine Cole

