# CLAN ANNUAL REPORT 2020-2021







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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.

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 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 signatory, contact can be made with the ACFID Code of Conduct Committee at http://www.acfid.asn.au/code-of-conduct/complaints.

### Acknowledgements

CLAN (Caring & Living As Neighbours) is headquartered in Sydney, Australia. We acknowledge the Wallumedegal peoples of the Eora Nation, the traditional owners of the lands on which we live and work, and pay our respects to Elders past, present and future.

We thank Zuha Zubair Ahmed for the beautiful artwork used on this cover, celebrating family and connectedness. Zuha developed a series of artworks for CLAN as part of an internship project to strengthen the capacity of children and young people to engage in the non-communicable disease (NCD) discourse, and we thank her most sincerely for such generosity of spirit, sharing her talents and gifts with us all in this way.





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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 (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) Optimise medical management (with a focus on preventive and holistic care).
- 4) Encourage family support groups.

5) Promote financial independence and reduce the financial burdens on families that lead to poverty.







# **GUIDING PRINCIPLES**



### 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.

**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.



# **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 Cole 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 – Stephanie Carde

Stephanie Carde was appointed CLAN's Public Officer in 2019 after volunteering in a Marketing and Communications capacity since 2017. Stephanie joins us from the state of Connecticut in the USA. She is currently working as a Marketing Coordinator in the not-for-profit sector. Stephanie received her Bachelor's Degree in Psychological Sciences with a double minor in Neuroscience and Criminal Justice and completed her double Master's in Counter Terrorism and Criminology in November 2020.





# **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), where is acts in a vital role to lead programmes for CLAN.



### Angie Middlehurst

Angie Middlehurst is 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 with 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 Lestradet award for Education and Advocacy, which is to be announced at the IPSAD virtual meeting in October 2021.





# **PRESIDENT'S REPORT**



An annual reflection would not be complete without acknowledgement of the COVID-19 pandemic.

The end of 2020 and start of 2021 have seem the world continue to redefine how we work in the context of the global COVID-19 pandemic Particularly for children and families living with non-communicable diseases (NCDs) and other chronic health conditions in the most vulnerable circumstances, COVID-19 has definitely brough additional challenges. However, we have also seen new opportunities, and CLAN is proud of our many innovative and committed partners who have helped us all adapt and negotiate this new environment so successfully.

CLAN's work has continued in the face of adversity, and so much of our strength has come from the amazing young people helping us at every step of the journey. CLAN's interns - both past and present – contributed so much to everything we do. Thank you to Kaitlyn Hunsberger, Stephanie Carde, Emma Santini, Annie Sanchez, Kevin Smith, Zuha Zubair Ahmed and Soni Porwal for your passionate commitment these last 12 months. In this reporting year we would also especially like to extend our warmest gratitude to Craig Rodgers, our honorary member for 2020-21, and Fish, one of our longest standing donors and champions.

An especial focus for CLAN this year has been the provision of Secretariat support to IndigenousNCDs, as this new global movement establishes itself as an independent, Indigenous led entity. On that note, especial thanks must go to the wonderful Tania Brown, Chief Executive Officer of IndigenousNCDs, and Dr Summer May Finlay, Chair of IndigenousNCDs. CLAN was proud to partner with IndigenousNCDs for the CSW65 event, as well as a range of other initiatives aimed at privileging and promoting First Nations voices within the global NCD discourse.

CLAN was likewise proud to partner with the Asia Pacific Pediatric Endocrinology Society (APPES) on a series of grants in Indonesia, Pakistan, India and Ghana to benefit childhood NCD Communities. The projects in Indonesia & Ghana were submitted to the World Health Organisation NCD Labs and the Ghanaian project was short-listed for special mention, while the Indonesian project was awarded winner of the category Meaningful Involvement of People Living with NCDs. At the core of this work, was Angie Middlehurst, who has tirelessly dedicated herself to education and support of families and children living with Type 1 diabetes throughout her career.

Many thanks also to Dr Andrew Twineamatsiko, Community Development Officer for CLAN Africa, for his contribution to the Human Rights Webinar for Youth Living with Type 1 Diabetes that CLAN was privileged to sponsor alongside Life For A Child and Insulin For Life. Dr Andrew's work with the Epilepsy Community of Uganda has built on achievements to date with the Nodding Syndrome Community of Uganda, and his remarkable mentoring abilities leave CLAN assured of the progress to come for CLAN Africa.

CLAN's Community Development Officers continue to contribute enormously globally contribute to our achievements with and for childhood NCD Communities. Dr Yen-Thanh Mac is a committed and pivotal member of CLAN's team in Vietnam and we thank her for her ongoing contributions. Likewise, we welcome Ms Misbah Hanif, a new addition to the incredible team at the National Institute of Child Health (NICH) in Karachi, Pakistan. Thank you both for all you do for so many.

Collaboration with our long-term partners around the world is core to CLAN's success. The recent publication in the International Journal of Neonatal Screening with co-authors from five different countries spoke to the power of these relationships. We hope this paper will help others learn from the strengths and successes of those who have travelled the journey so far, and ensure future generations of passionate allies may likewise apply CLAN's strategic framework for the benefit of children living in the most vulnerable circumstances.

A sufficient amount of gratitude cannot be expressed to all those who support CLAN, but once more – thank you. Every person who involves themselves in, or supports CLAN's work in anyway, is an immeasurable gift not just to this organisation but also the children and families we have the privilege of working with. Your charity and passion make the impossible seem possible. For this, and everything else you do, thank you.

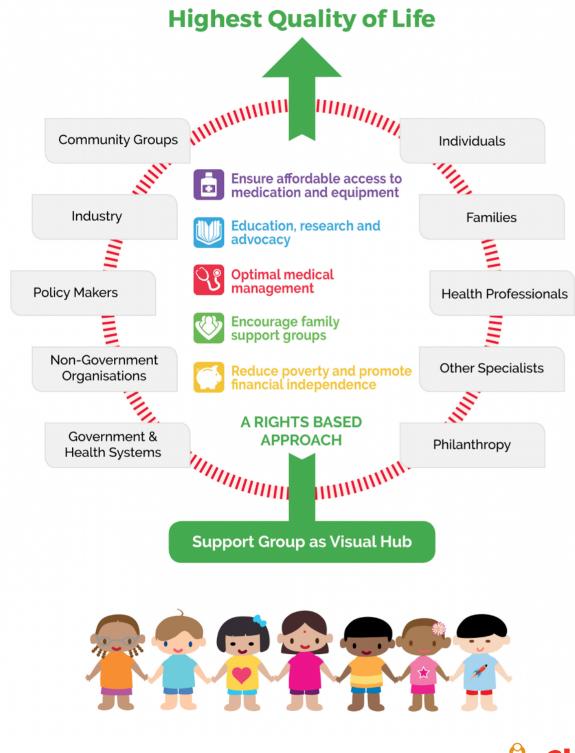
Sincerely, Kate Armstrong B Med DCH MPH FAFPHM DrPH



### 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.









### HONORARY MEMBER: CRAIG RODGERS

Craig 'Craigus' Rodgers graduated from medicine at the University of Newcastle with the wonderful Dr Kate Armstrong quite some time ago. In 2000, Craig completed his training with the College of General Practitioners. Following this GP training he worked in a combination of General Practice and for a public health service known as the Kirketon Road Centre (KRC) that provided free treatment and care to people who inject drugs (PWID), sex workers and 'at risk' young people. It was while working at KRC that he was inducted as a founding Fellow of the Chapter of Addiction Medicine in 2004, which was a new speciality college of the Royal Australasian College of Physicians.



Over the past 20 years, Craig has continued to work in both the drug and alcohol sector and general practice with roles at the Kirketon Road Centre, East Sydney Doctors, the Sydney Medically Supervised Injecting Centre. Since 2012, he has been working as a Staff Specialist in Addiction Medicine at St Vincent's Hospital. Craig is also a conjoint lecturer with the University of New South Wales and has contributed to registrar and GP training in the areas of Addiction Medicine, HIV and Sexual Health.

Craig is a long-term supporter of CLAN, motivated to support our effort for change for children living chronic health conditions around the world. CLAN is especially grateful for his support for the Epilepsy and Nodding Syndrome Communities in Uganda. Craig's support has made a difference to the lives of many.

Craig donates regularly, supporting the variety of projects which arise over time. You can be like Craig too! Regular donations mean CLAN's work can achieve sustainability and consistency.



### **NOTABLE DONOR: FISH**

Meet Fish: Devoted biker, God's Squad member, father of seven, person living a fulfilling life with diabetes and long-term donor to CLAN.

In May 2011, Fish and his dog Zeke set off on an 873km journey from Sydney to Melbourne to raise awareness of Diabetes and raise funds for CLAN's activities to support children with endocrine conditions. In the years since, Fish has continued to support CLAN's work, and enabled us to undertake some pivotal projects for Diabetes Communities internationally.

This year, Fish was very pleased to hear the Pedia Project in Indonesia was awarded as a winning entrant in the inaugural World Health Organisation NCD Labs.

We are truly indebted to Fish for his ongoing support to CLAN and proud to have Fish as a caring and compassionate member of CLAN's extended family.



# REPORT ON ASIA PACIFIC PAEDIATRIC ENDOCRINE SOCIETY (APPES) GRANTS

Sincerest thanks to each and every one of the recipients for the incredible work you did (supported so generously by your incredible mentors in-country), honouring the inaugural CLAN-APPES grants. Especial recognition to the teams in Indonesia and Ghana for your recent recognition in the inaugural WHO NCD Labs (https://www.knowledge-action-portal.com/en/ncd\_lab/featured\_projects).

### Indonesia

This project was submitted to the World Health Organisation: NCD Lab: Highlighting innovative solutions to accelerate progress towards achieving the NCD related SDGs, a WHO platform to raise awareness of NCDs and to identify cross-cutting initiatives working towards reducing the global burden of NCDs and mental health conditions. And the winner was Indonesia, for the category of Meaningful Involvement of People Living with NCDs!

### Ghana

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"Connect and Learn: a cross-organizational, internet-based peer leadership socioemotional support model for young people with T1D in Accra and Kumasi, Ghana"

CLAN is so grateful to all of our grant recipients for everything they have achieved. We acknowledge each of you have delivered outstanding results. Your efforts have been exceptional - not least of all because of the hardships faced during the public health emergency of COVID-19, a global pandemic that continues to challenge everyone. CLAN is keen to continue doing all we can to promote your projects and successes.

### Notable Achievements

### Indonesia

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"Connect and Learn: a cross-organizational, internet-based peer leadership socioemotional support model for young people with T1D in Accra and Kumasi, Ghana"



# APPES-CLAN GRANT Project 2020: Indonesia

The Pedia Project Team have been working in Indonesia to improve the quality of Type 1 Diabetes Care Management, optimising an existing app as an educational platform, and connecting the app with the National Registry System. A variety of educational resources have been developed, and distributed in the Bahasa language, to increase the capacity of the children and families living with Type 1 Diabetes. This project aimed to improve the quality of Type 1 Diabetes care management by providing insight to the effects of the COVID-19 pandemic on the Type 1 Diabetes community, through the development and distribution of educational resources and by establishing a dialogue between healthcare professionals and those living with Type 1 Diabetes.

Project title: Effects of COVID-19 pandemic in diabetes management in children and adolescents with T1D in Indonesia. (The initial title was 'Nationwide survey about current management of T1D in children and adolescents in Indonesia', but this was amended when the pandemic emerged).

Local project team:

- · Project Mentor: Dr Aman Pulungan
- · Project Leader: Dr Ghaisani Fadiana
- · Content and Layou: Kartika Qonita Putri
- · Illustration and Design: Syifa Fahrurozi

CLAN Committee Representative and mentor: Angie Middlehurst, Paediatric Diabetes Educator, Sydney, Australia.

Project aim: To improve the overall quality of type1 diabetes care management by involving all important stakeholders, such as paediatricians, patients and families through optimizing an existing mobile health app as an educational platform and integrating it with the national registry system.

h optimizing an existing mobile health app as an educational platform and integrating it with the national registry system.

### Education materials developed in Bahasa:

- Development of an education flyer was developed and disseminated with the questionnaire
- A daily journal was completed
- A flip chart for one on one or small group education sessions was commenced
- Communication established with Angie who sent education resource ideas and modules for team consideration
- A manual/guide book for parents is in the pipeline (Angie reminded the team that the Australian parent manual had been planned to be translated a few years ago in conjunction with Professor Geoff Ambler at the Children's Hospital, Westmead team to follow up). Currently translated, progress: 50%
- The team plan for face to face education sessions using the developed materials at the end of the project term



The team plan to incorporate all developed education materials into an existing mobile app remembering that under-privileged families may not be able to access this app and will still require paper versions. There were difficulties organising meetings due to COVID; the team investigated existing digital elearning schemes; content would be the flip chart; proposal planned to discuss with app developer.



Caring & Living As Neighbours

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## APPES-CLAN GRANT PROJECT 2020: National Institute of Child Health (Nich), Karachi, Pakistan

CLAN has been working closely with Professor Jamal Raza and his team at NICH to deliver essential medicines to the doorstep of children living with Congenital Adrenal Hyperplasia (CAH) living in the most challenging circumstances in Pakistan. Although these medications essential, they have not always been affordably available to these families. This project aimed to improve the quality of life and care in children living with CAH by making essential medicines are accessible, thus improving compliance and health outcomes. The uninterrupted supply of medicines to households resulted in a considerable increase of adherence. This project proved to be particularly advantageous as it occurred during the COVID-19 pandemic and overcame significant barriers to the effective administration and provision of medicines that would otherwise have faced these families.

Project title: Availability of essential medicines at the door step of CAH patients to optimize the quality of life in children living in resource poor settings, a CLAN initiative.

Principal Investigator: Professor Jamal Raza, Director of NICH

Objective: To deliver the essential Congenital Adrenal Hyperplasia (CAH) medicines at patient's door step for better compliance and adherence to medicines.

Study Design: Descriptive and Cross-sectional study

#### A recent update from CLAN's current Community Development Officer in Pakistan, Misbah:

"My Name is Misbah Hanif, Community Developing Officer at the National Institute of Child Health, Karachi, Pakistan.

Professionally I am a clinical geneticist and have been working here for 5 years at NICH. A few months back I joined CLAN as CDO. In a very limited period of my journey with CLAN, I got into an already running project which was aimed to provide CAH medicine to poor patients free of cost at their doorsteps.

A significant rise can be seen in the registered patient of this project (up to 80). Patients are living outside of other cities than Karachi, and have a very weak financial background. It was almost impossible for them to buy these costly medicines (Hydrocortisone and Florinef). Perhaps they could not afford the travel expense if we would have been providing this medicine at the hospital. This CLAN project is helping them by delivering medicine at their doorstep through TCS Karachi. However, it is not an easy task for us to get the medicine each month for such a large community of patients. Every month we struggle a lot to make it done for the purpose we contact several Pharmacies for the availability and also talk to several NGOs and persons who can help us buy medicine for our underprivileged patients. For the convenience of our patients, we made a WhatsApp group through which patients and their families can get into touch and talk about their issues about current health, medicine supply, and follow-up visits effortlessly. I and my dedicated team are trying to facilitate them as much as we can do with such limited resources.

Besides all this we also maintain a registry in which each of the patients includes from the project, OPD or emergency, so far we have 339 registered CAH patients and 938 diabetic patients in our peds registry. A mobile APP about paediatric endocrinologists is also a big achievement from our side in which senior paediatric endocrinologists, pharmacies, and detail about the diseases are there, though we still need some promotions."



**Conclusion**: Patient's adherence to the medicine and compliance markedly increased due to uninterrupted supply of medicine. This was an extra advantage during COVID-19 induced lock-down in entire country due to absent mass transit.



# APPES-CLAN GRANT Project 2020: India



Project Title: Understanding health outcomes in young people living with Thalassaemia in India

**Principal Investigator:** Dr Koushik H, Assistant Professor, Department of Paediatrics, Kasturba Medical College, MAHE, Manipal, India.

**Mentor**: Dr Vijalakshmi Bhatia, Professor, Department of Endocrinology, SGPGI, Lucknow, India. Project Aims: This project aimed to better understand the nature of endocrine deficiencies in children with transfusion dependent Thalassaemia Major, and initiate community development efforts so that all children can be optimally supported to enjoy the highest quality of life possible.

**Project Methods:** All children enrolled ages 5 years and over were screened for short stature, hypothyroidism, hypoparathyroidism, diabetes mellitus, adrenal insufficiency, metabolic bone disease. Necessary action was initiated by the treating team whenever endocrine deficiencies were found. Community development activities were planned in accordance with CLAN's five pillars.

**Progress:** This project was severely interrupted by the COVID-19 Pandemic. At the time of reporting 30 children with Thalassemia Major hae already been recruited and complete endocrine evaluation was conducted. Approximately 10 more children are yet to be recruited, and this is expected to be completed by July 2021. The remainder of the grant activities will focus on community development activities and will include:

-**Pillar 2** - Health education pamphlets in Kannada (local language): We propose to make small, informative, colourful pamphlets focusing general health, diet, prevention of long-term complications affecting children who are living with thalassemia and disseminate it.

-**Pillar 4** - Community events - once the pandemic situation alters and it is deemed safe a range of activities will be considered. The majority of our thalassemia children belong to lower or middle class family. Families are already burdened economically and emotionally by periodic blood transfusion, chelation, repeated hospitalization. Holidays, picnics, outings with family and friends are mostly difficult or not affordable to many.

Hence, the team propose to conduct a day long camp or meet of thalassemia families and treat them in a nearby resort or beach. We also would like to involve different stakeholders involved in their care like paediatricians, nurses, social workers, voluntary student organizations. We can have fun games, group activities, cultural programmes. Also, preventive health checks, health education session involving prevention of long-term complication, dietary advice, handling psychosocial issues can be planned. It will bring different families together, boost their morale, enable us to form a sustainable support group.

**Next steps**: The team are already planning initiatives for other NCDs. Health education materials for CAH and Type 1 DM patients are needed for this other large group of children. As a part of health education we propose to make health education material in the form of handouts, pamphlets addressing these issues. We intend to cover hypoglycaemia care, sick day management, insulin administration in type 1 DM and general issues, stress dose coverage in CAH. These educational materials will improve the understanding about the disease and improve their quality of life





### In conjunction with PenPals United (PPU) and Diabetes Youth Centre (DYC).

CLAN is working in conjunction with PenPals United (PPU) and Diabetes Youth Centre (DYC) to empower young people in Accra, Ghana, living with Type 1 Diabetes through Diabetes self-management education and peer mentorship support. Through accessible, sustainable, culturally and age relevant, internet-based education and support, young people living with Type 1 Diabetes in Accra, Ghana, can experience a higher level and better quality of care, resulting in improved quality of life. Support groups and open channels of communication allow people living with the condition and their families to feel supported as part of a community. This project aimed to empower young people with the knowledge to independently manage their Type 1 Diabetes.

**Project Title:** To implement sustained education and peer support to children with type1 diabetes (T1D) in the Accra area of Ghana

### Local project team:

•Diabetes Youth Care (DYC) •Dr Elizabeth Bankah, Greater Accra Regional Hospital •Irene Agyemang

### **PPU team:**

·Hannah Anolik, ·Jack Terchluse · Dr Santosh Gupta

USA contact & mentor: Dr Nana Ama Barnes

CLAN & PPU committee representative and mentor: Angie Middlehurst, Paediatric Diabetes Educator, Sydney, Australia

**Project Description:** This project empowers and educates young people living with diabetes through sustainable, culturally and age-relevant, internet-based diabetes self-management education and peer mentorship support. Living with diabetes in Ghana is a challenge for both the person with T1D and their families, who often feel isolated, receive misinformation and little support. This causes problems with accessing health facilities and following up with care, resulting in young people developing complications and poor mental health. DYC is a support network for young people living with T1D in Ghana, and helps ease the financial cost of diabetes products. Once introduced, DYC and PPU pledged to develop culturally and age relevant, evidence-based content in "Peer Leadership " and "Diabetes Self Management Education" modules. These are computer and mobile accessible on PPU's website, to provide for sustainable education based in peer support and peer education.







### **Project Aims:**

- 1. To implement sustained education and peer support to children and young people with T1D in the Accra area of Ghana
- 2. To empower and educate children and young people living with T1D through sustainable, culturally and age relevant, internet based diabetes self management education and peer mentorship support
- 3. To increase the capacity of children and young people with T1D to deliver peer support, and improves context-specific knowledge and management of diabetes
- 4. To encourage the increase of the capacity of children and young people with T1D to deliver context-specific T1D-related knowledge and peer support, resulting in the increased health and well-being of young people.

### Project Objectives:

- 1. Two culture and age-appropriate online modules are created in consultation with peer leaders
- 2. 50 young people from Accra complete DSME training. 10 people complete peer mentor training.
- 3. The peer support program is sustainable. Target: Peer mentors provide training and support to 40 peers.
- 4. The peer support program is peer-evaluated and continues to stay culturally relevant. Target: 30 Peer Leaders and other participants using online PPU modules voluntarily complete review quizzes and pre- and post-module survey.

**Result:** We are delighted to report that the project was a success with education modules made available on the PPU website. A pre and post survey was conducted and throughout the project regular updates from PPU/DYC on the project progress were provided to CLAN by Angie Middlehurst. Thanks must go to everyone who participated and supported the project and made it the success that it is.





## **CLAN'S INTERNS**

### Partnership with Lehigh University



### Prepared by Emma Santini

Founded in 2008, Lehigh University's United Nations Youth Representative Program matches UN-accredited NGOs like CLAN with high-achieving undergraduate and graduate students who serve as that NGO's voice at the United Nations. Youth Representatives Emma Santini and Annie Sanchez are positioned to meet with global decision-makers, participate in international conferences, and moderate briefings broadcast worldwide. They advocate on a variety of platforms related to CLAN's agenda at the United Nations and worldwide, furthering our mission through new channels. The Lehigh University UN Youth Representative Program's relationship with CLAN is one that is longstanding, advantageous, and critical for the implementation of sustainable, UN-based solutions to childhood NCD burdens.

Whitney Szmodis was the primary advisor of current Youth Representatives Emma and Annie and previous Youth Representative Kevin Smith, until moving on from the role mid-2021. She displayed an incredible passion for CLAN's mission and constantly sought opportunities for growth. Her support has helped CLAN's advocacy efforts tremendously and we are grateful for her contributions to the organization. Whitney accepted a new position in August of 2021 and will no longer have a prominent role within CLAN or the UN Youth Representative program. Nonetheless, her impact on CLAN is one that will endure over the long term and we wish her success in her future endeavours.

Emma Santini



Annie Sanchez



### Kevin Smith

Kevin was engaged as a CLAN UN Youth Representative through this program, ending his time through this past reporting year. CLAN is grateful for Kevin for his extensive work with CLAN. It is only fitting to reflect on Kevin's role with CLAN, to recognise his valuable contributions to CLAN's mission.

Kevin was born and raised in Jamaica and moved to the US in 2016. He is currently completing his PhD in Economics, focusing on health economics, researching ways to make the healthcare market more competitive, as well as the economic and medical impacts of prenatal outcomes. Kevin was an invaluable member of CLAN's Youth Representative team at Lehigh University in Pennsylvania, and is passionate about the importance of an intersectional approach to public health, in order to truly combat the root causes. Kevin's work is vital to redressing the prevalence of these diseases in future generations.



Kevin's role with CLAN was as one of the United Nations Youth Representatives. He was initially focussed on a project in Uganda with the Nodding Syndrome community, looking at ways this project could be more effective. He later directed his energy to projects dealing with IndigenousNCDs, focussing on policy briefs, as well as working closely with CLAN's partners in Pakistan who were working with the CAH community. He and Emma Santini wrote a chapter in an upcoming book on this project, and how we may be able to use the idea of global citizenship in our teaching and learning.





### **CLAN'S INTERNS**



### Partnership with Global Experiences

### Zuha Zubair Ahmed

Zuha is a third year university student at Carleton University in Canada. Her dual major in anthropology and literature lead her to CLAN to work for the summer as an intern in June 2021.

### Here's what Zuha had to say:

Through CLAN I was able to learn about the health inequalities, especially with non-communicable diseases (NCDs), faced by Aboriginal and Torres Strait Islander peoples in Australia.

Additionally, I was honoured to be invited through CLAN, to the Our Views, Our Voices meeting, hosted by NCDAlliance, which was a platform for advocacy and an educational opportunity for me to understand the Global impact of NCDs. The meeting proved how much of an impact awareness and advocacy can have on people with NCDs and emphasised the importance of meaningfully involving people with NCDs with their community.

During my time in CLAN I have had the pleasure of compiling awareness messages as well as creating illustrations for future social media posts and projects. Jointly, I worked with Indigenous NCDs on the development of the Toolkit for Aboriginal and Torres Strait Islander peoples with NCDs. I had also spent some time researching how the lack of Aboriginal languages impacts the health outcomes of Aboriginal and Torres Strait Islander Peoples.



### Soni Porwal



Soni is a current graduate of International Relations (IR) from the University of Melbourne. She has keen interests in public policy, sustainability, gender roles in IR and international trade. Soni interned with CLAN as part of her Work Integrated Learning module from March 2021. As part of CLAN's internal staff training and development efforts, Soni researched and prepared a series of training presentations on the over-incarceration of Aboriginal and Torres Strait Islander children in Australia. Throughout the process of learning more about this topic, Soni met with a range of highly knowledgeable and influential individuals, including Yvonne Weldon, the first Aboriginal-Australian candidate for Lord Mayor of Sydney.

### Here's what Soni had to say:

"Interning with CLAN has been such an amazing experience filled with encouragement, constructive insights, guidance and constant support from my supervisors Dr. Kate Armstrong and Cath Cole. I was delighted to work for them and direct my efforts towards learning more about the Australian policies for my research and various universal rules and rights conventions and declarations for. I was thrilled and very nervous to have spoken and connected with Tania Brown and Yvonne Weldon, who are high profile Aboriginal leaders in Australia. Presenting in front of them and getting their insights on future plans and goals was an amazing professional development experience. I am overwhelmed with the personal support given to me by Kate and Cath during my internship and I will always cherish this experience with sincerity and further volunteering support for CLAN."



INDIGENOUSNCDS Prepared by Tania Brown

The IndigenousNCDs Movement was founded in July 2018 in response to a Draft Declaration released ahead of the Third United Nations High Level Meeting on Non-Communicable Diseases (UNHLM on NCDs, held in New York in September 2018). The draft did not include any mention of Indigenous peoples, despite the fact Indigenous peoples are inequitably burdened by NCDs and offer innovative solutions for change.

The object of IndigenousNCDs is to promote the prevention and control of NCDs by and among Indigenous peoples of the world through:

- 1. promotion of Indigenous peoples' leadership of and input into the effective treatment of NCDs in and among Indigenous peoples of the world;
- 2. education of international organisations, governments, health providers, community and other organisations about the unique and effective contributions and perspectives that Indigenous persons bring to the prevention and control of NCDs in and among the Indigenous peoples of the world.

### What we do:

- Facilitate opportunities for Indigenous Peoples to participate at the National and International level to inform and shape the NCD dialogue
- Promote Indigenous-led NCD solutions and successes
- Educate stakeholders regarding unique NCD-related issues Indigenous Peoples face
- Advocate for Indigenous perspectives to be included in all NCD actions
- Form strong and meaningful partnerships with Peak Indigenous organisations

# In joint partnership with CLAN, the IndigenousNCDs movement has to date facilitated:

- Briefing documents prepared for UN Civil Society event in July 2018
- Twitter Festival in September 2018, with ongoing Twitter engagement (1,193 followers)
- Indigenous persons leading development of publications relevant to IndigenousNCDs
- Representation at UN Civil Society event on NCDs and Third UNHLM on NCDs in 2018
- Publications made available on WHO KAP (Knowledge Action Portal)
- Participation in WHO #BuildBackBetter Webinar on COVID19 in 2020
- Indigenous representatives participating in WHO / UN events (to date Australia, Canada, New Zealand and USA represented)
- IndigenousNCDs Chairperson invited to give key-note address at WHO NCD event (alongside Dr Tedros)
- Participation in WHO Consultation on PLWNCDs in 2021
- Consulted on Global Action Plan for International Decade of Indigenous Languages in 2021
- Participation in 2021 Commission on the Status of Women (hosted by UN Women) focusing on work Indigenous women are achieving in tackling NCDs and Aboriginal and Community Controlled Health Sectors model of care
- Participation in WHO's Global Coordination Mechanism on NCDs through CLAN
- Submission to 2021 ECOSOC High Level Meeting





The 65th Session of the Commission on the Status of Women, held in March 2021, was a notable forum for amplifying Indigenous voicing and framing CLAN's work in the sphere of Indigenous rights. In partnership with IndigenousNCDs, and with over 135 attendees, 13% of whom were First Nations people, CSW65 was a huge success.

### Prepared by Emma Santini

On March 16, CLAN and IndigenousNCDs co-hosted a parallel event at the UN Women's NGO Commission on the Status of Women 65th Forum titled "Putting Indigenous Women First in Tackling NCDs". CLAN is proudly serving at the Secretariat for IndigenousNCDs.

IndigenousNCDs is an Indigenous-led movement seeking to promote the voices and experiences of Indigenous peoples within the global non-communicable diseases (NCDs) discourse. This event primarily placed a spotlight on Indigenous women as mothers and primary caregivers of children living with NCDs. Women are in a powerful position to be active partners in driving change, and panellists highlighted the invaluable contributions of women in maintaining the health of their children and communities. To address global health inequities, CLAN believes it is essential to empower women in the fight for children's equal rights to health, particularly within resource-poor settings and disproportionately affected populations like Indigenous communities.

Keynote speaker Kaitlyn Hunsberger, a member of the Yavapai Nation in Arizona, USA and former intern of CLAN, discussed the matriarchal systems within Indigenous communities and highlighted the accomplishments of Native women who have spurred enormous shifts in the mobilisation of healthcare, education, and politics. At a time of huge challenge during COVID-19, Kaitlyn conveyed the strength and resilience of women in her communities and their inspiring, creative, and innovative solutions to keep communities safe. She concluded her piece by emphasising that there is a "new era ahead of us, one that involves Indigenous voices in places where they are making decisions about us, without us". Both CLAN and IndigenousNCDs were proud to support the voices of First Nations women like Kaitlyn who are dedicated to advancing principles of equitable health within their communities and motivating others to do the same.

This excerpt is continued on page 22.





Poster for the IndigenousNCDs/CLAN Virtual NGO CSW65 Forum:





CLAN is proud to be the inaugural Secretariat of — IndigenousNCDs, together presenting: —

# Putting Indigenous Women First in Tackling NCDs

### Tuesday, March 16 at 3:00 PM EDT

Come learn about Indigenous women as mothers and primary caregivers of children living with non-communicable diseases (NCDs). Women are in a powerful position to be active partners in driving change, and CLAN will discuss their invaluable contributions to maintaining the health of their children.



### with Speaker Kaitlyn Hunsberger

member of the Fort McDowell Yavapai Nation in Arizona, USA

@CLANchildhealth www.clanchildhealth.org

@IndigenousNCDs

www.clanchildhealth.org www.indigenousncds.org

#CSW65

#IndigenousNCDs

### VIRTUAL NGO CSW65 FORUM65

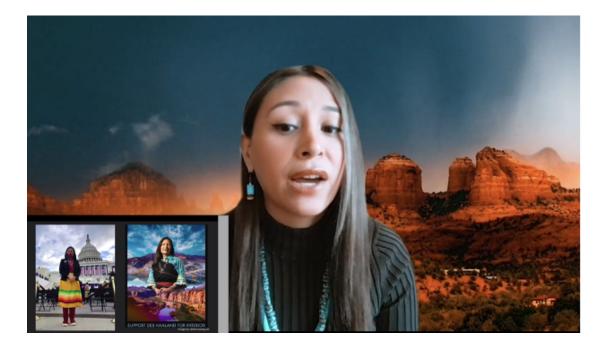
Register here to attend!







Two of CLAN's Youth Representatives to the UN, Emma Santini and Kevin Smith (both students at LeHigh University), also shared an update on the work of CLAN to maximise the quality of life for children and their families who are living with chronic health conditions in resource-poor settings. CLAN's work across the globe follows a rights-based, community development model, with a strategic framework for action encompassing 5 Pillars: affordable access to medication and medical equipment; education, research and advocacy; optimisation of medical management; encouragement of family support networks; and promoting financial independence. Kevin shared a project that CLAN started in December 2019 with the National Institute of Child Health (NICH) in Karachi, Pakistan, that assisted families of children living with Congenital Adrenal Hyperplasia (CAH). A pilot project funded the delivery of essential medicines to the homes of 50 CAH community members identified as living in the most vulnerable circumstances. With near-universal compliance and follow-up achieve with all 50 children throughout the COVID-19 pandemic, it was a truly remarkable outcome for the families involved and spoke to the importance of promoting affordable access to essential medicines for those most in need.



### Some moving quotes from Kaitlyn's powerful speech to CSW65:

"Colonial violence led to public health injustices and crises within Indigenous communities... This history matters in this moment because our communities remember. As individuals, our bodies remember. And because of this, Native people may be experiencing anxiety and distrust in our government's commitment to public health. This is why "indigenizing" community care is so critical as we work to protect Indigenous communities and people from COVID-19."

"Despite the challenges, the crisis highlights the innovation and resiliency that has defined Native people for centuries. For generations, Indigenous nations have relied on their strength and traditions to help them navigate hardship. And in times of great uncertainty, it's imperative that communities remember this resilience."







E/CN.6/2021/NGO/94

United Nations

### Economic and Social Council

Distr.: General 9 December 2020

Original: English

Commission on the Status of Women Sixty-fifth session 15–26 March 2021 Follow-up to the Fourth World Conference on Women and to the twenty-third special session of the General Assembly entitled "Women 2000: gender equality, development and peace for the twenty-first century"

### Statement submitted by CLAN (Caring & Living as Neighbours) Incorporated, a non-governmental organization in consultative status with the Economic and Social Council\*

The Secretary-General has received the following statement, which is being circulated in accordance with paragraphs 36 and 37 of Economic and Social Council resolution 1996/31.

### Read CLAN's ECOSOC statement to CSW65 in full below:

Caring & Living as Neighbours (CLAN) supports the sixty-fifth session of the Commission on the Status of Women and recognises the imperative need to advance gender equality as outlined the Beijing Declaration and Platform for Action (1995). CLAN would like to acknowledge the Wallumedegal peoples of the Eora Nation, the Traditional Owners of the land on which we are headquartered. CLAN also acknowledges that the present statement is written and submitted on the traditional lands of the Lenape people, on which the United Nations is headquartered in New York City. CLAN pays its respects to Elders past, present and emerging.

CLAN, founded in 2004, is an Australian non-government organisation (NGO) dedicated to maximising quality of life for children and their families who are living with chronic health conditions in resource-poor settings of the world. As stated in the United Nations Convention on the Rights of the Child (UNCRC), all children with special health requirements have a right to the care needed to enable them to live the healthiest and most fulfilling life possible (Articles 3, 6, 24; 1990).







CLAN operates under a rights-based strategic framework for action that promotes a community development approach to redressing inequities experienced by children living with chronic health conditions in resource-poor countries. CLAN's model seeks to focus multisectoral collaborative efforts on five pillars considered essential to achieving the highest possible quality of life for these communities. The five pillars are focused on:

Access to medicines and equipment; Access to education, research and advocacy; Optimisation of medical management; Encouragement of family support groups; Actions to reduce financial burdens and promote financial independence.

An exemplary utilisation of CLAN's strategic framework was most recently observed in Pakistan, where collective action advanced access to essential medicines for treatment of Congenital Adrenal Hyperplasia (CAH). In 2020, local production of hydrocortisone tablets in Pakistan at an extremely low cost (Rs2.2/tablet' AUD 0.018/tablet) commenced after years of advocacy, ensuring this life-saving medication was affordably available for all persons living with CAH in Pakistan. This achievement led to a CLAN pilot project run by the National Institute of Child Health (NICH) in Karachi, which had a one-hundred percent success rate during the COVID-19 pandemic, and it is reasonable to assume all of these children would otherwise have suffered enormously had the project not been running.

CLAN will focus on the following critical areas of concern in 2021, based on the Beijing Platform for Action. Our call to action is dedicated to improving the lives of the poorest families and children suffering from non-communicable diseases and other chronic health conditions all over the world. CLAN acknowledges how these issues particularly affect women, especially Indigenous Women throughout the world.

(Women and Health): CLAN is committed to the Beijing Platform for Action through our five pillars that promote women and health through affordable access to medication and equipment, education, optimisation of medical management, encouragement of family support networks, and reducing financial burdens on families. There needs to be a particular focus on the unique cultural needs of Indigenous women. What also needs to be recognised is the ongoing impact of colonisation and racism. Indigenous women are often some of the most marginalised within their own countries. With communities engaged in the design and deliver of relevant services.

According to the Beijing Platform for Action paragraph 90, women have different and unequal access to, and use of, basic health resources, including primary health services for the prevention and treatment of childhood diseases, malnutrition, anaemia, diarrhoeal diseases, communicable diseases, malaria and other tropical diseases and tuberculosis, among others.

This aligns with CLAN's first pillar of promoting access to medication and equipment. This can be achieved where there is political will, and collaborative action by medical device manufacturers and policy makers to make drugs, therapeutics, and medical equipment more affordable and accessible. This is especially important for families with girls who may not get equal access to medical treatments.







Additionally, this portion of Beijing Platform for Action touches on pillar five of CLAN's framework for action, which aims to reduce financial burdens and promote financial independence. We also note that too often mothers are left to care for children with severe and chronic health conditions in resource poor settings.

Beijing Platform for Action paragraph 107 discusses creating and support programmes in the educational system, in the workplace and in the community so that opportunities to participate in physical activity and recreational is equally available to girls and women of all ages.

This goal of the Beijing Platform for Action directly aligns with CLAN's second pillar of improving access to education with a community focused approach. CLAN approaches access to education by empowering families and communities to get the resources they need so that children will not only be able to attend school by also complete to their full potential.

Finally, one of the main goals stated in the Beijing Platform for Action in paragraph 106, is to support non-governmental organisations working on women's health and help develop networks aimed at improving coordination and collaboration between all sectors that affect health.

This holistic approach directly aligns with the third and fourth pillars of CLAN. Pillar three focuses on the optimisation of medical management so those living in the most vulnerable circumstances can access multidisciplinary care. Pillar four focuses on strengthening NCD Community networks and partnerships to reduce social isolation and empower families. For women and girls these networks are especially important as many times women with chronic illnesses may be overlooked by traditional health care systems.

#### Conclusion

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

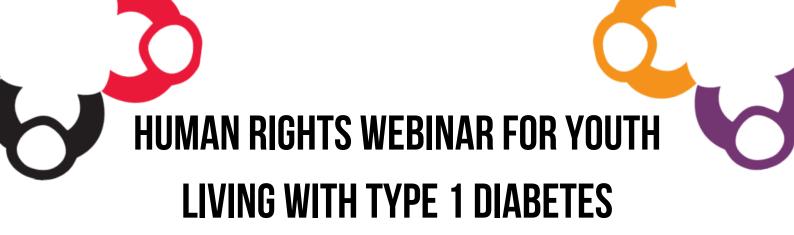
CLAN calls upon the Commission on the Status of Women, UN-Women, and other relevant United Nations entities to acknowledge women as mothers and primary caregivers of children living with NCDs. This puts women in a powerful position to be active partners in driving change, and CLAN advocates for recognition of their invaluable contributions to maintaining the health of their children. See: We All Have a Role to Play: Redressing Inequities for Children Living with CAH and Other Chronic Health Conditions of Childhood in Resource-Poor Settings in the International Journal of Neonatal Screening, published by CLAN and partners (2020).

CLAN calls upon the Commission on the Status of Women, UN-Women, and other relevant United Nations entities to recognise the vast potential of the WHO's plan to establish a Youth Council and the critical nature of being inclusive of Indigenous Youth. Although Indigenous Peoples make up only five percent of the global population, they account for about fifteen percent of the extreme poor. Indigenous Youth face unique cultural, social, political, and commercial determinants of health, underscoring the vital need to meaningfully engaged Indigenous Youth in the global NCD discourse, and ensure their voices are health.

CLAN calls upon the Commission on the Status of Women, UN-Women, and other relevant United Nations entities to carefully consider resourcing required for an inclusive Youth Council. It is essential for WHO's Youth Council to not only to include young people living with NCDs from high income countries and families, but also young people living with NCDs in resource poor settings.

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





### Prepared by Dr. Andrew Twineamatsiko

### Our Rights to Health in Africa: A Type 1 Diabetes Youth Advocacy Workshop

14th June 2021 was a wonderful day for advocates and the Type 1 Diabetes community, an interactive virtual session organised in partnership with Caring and Living As Neighbours (CLAN), Life For A Child and Insulin for Life.

Together with other panelists and United Nations Special Rapporteur Dr. Tlaleng Mofokeng as the Key note speaker we shared insights onto the relationships among, human rights, advocacy and Type 1 Diabetes to 160 participants from all regions with majority from Africa.

I used the opportunity as a panelist to share the successes and achievements made in our CLAN supported Uganda based projects with Nodding syndrome and Epilepsy communities using CLAN's rights based and community centred 5-Pillar model.

These pillars; access to medicines and equipment, education, research and advocacy, optimal medical management, establishing support groups and reducing financial burden imposed by management of chronic illnesses on families have proven to be fundamental in uplifting the strength of communities. Employing these rights-based pillars for Type-1-Diabetes communities will play a long mile towards achieving a proper and quality life for all.

I strongly believe post-workshop, we have a very strong community of advocates all over the region and the world at large. Organising more workshops will eventually change the world for better.

Thanks to CLAN, LFAC and Insulin for Life for creating this wonderful opportunity.

### Dr. Andrew Twineamatsiko Community Development Officer, CLAN Africa







### Vietnam

CLAN has been working with and supporting the Duchenne Muscular Dystrophy (DMD) Community in Vietnam. The most recent project is the joint purchase of harmonicas to help strengthen the lungs of young people living with DMD.

This project's goal was to connect people living with DMD and their families, provide them with support and introduce the harmonica as a creative means of managing the condition. Practicing the harmonica encourages diaphragmatic breathing, which can result in increased oxygen intake and lung function. The young people and their families were also given insight into the ICF (International Classification of Functioning, Disability and Health), which empowers young people with knowledge to understand and communicate about their experiences with DMD.

The project included a Parents' meeting, where families were able to connect with each other and discuss the means by which they can support their children who are living with DMD. Along with this, Community Development Officer Dr. Yen-Thanh Mac and Harmonic Instructor Phat Vo introduced the harmonica to the young people, and encouraged them to play together online. Throughout the project, Yen-Thanh and Phat visited the DMD community members to connect with them and follow up with their progress.

CLAN thanks Dr Yen-Thanh and Mr Phat Vo for their efforts on this project.





### Fiji

CLAN was proud to continue supporting the OI Community of Fiji with donations of bisphosphonates for injection to Dr Ilisapeci Tuibeqa and her amazing team at the Suva War Memorial Hospital in September 2020. CLAN has been collaborating with Dr Ili and the OI Community since 2016, and will continue our joint advocacy efforts to secure longer term, affordable access to this life-changing medicine for children in Fiji.





# **INTERNATIONAL JOURNAL OF NEONATAL** SCREENING (IJNS) PAPER

CLAN was proud to collaborate with many of our long-term partners from several countries on a journal article outlining CLAN's Strategic Framework for Action. This article outlines the "how" of CLAN, and offers a blueprint to follow, for others keen to replicate this application of strategy.

Sincerest thanks are extended to the outstanding co-authors.

This article was nominated for "Editor's Choice".

### Below is the abstract for the piece:

CLAN (Caring and Living as Neighbours) is an Australian-based non-governmental organisation (NGO) committed to equity for children living with chronic health conditions in resource-poor settings. Since 2004, CLAN has collaborated with a broad range of partners across the Asia Pacific region to improve quality of life for children living with congenital adrenal hyperplasia (CAH). This exploratory case study uses the Knowledge to Action (KTA) framework to analyse CLAN's activities for children living with CAH in the Asia Pacific. The seven stages of the KTA action cycle inform a systematic examination of comprehensive, collaborative, sustained actions to address a complex health challenge. The KTA framework demonstrates the "how" of CLAN's approach to knowledge creation and exchange, and the centrality of community development to multisectoral collaborative action across a range of conditions, cultures and countries to redressing child health inequities. This includes a commitment to: affordable access to essential medicines and equipment; education, research and advocacy; optimisation of medical management; encouragement of family support groups; efforts to reduce financial burdens; and ethical, transparent program management as critical components of success. Improvements in quality of life and health outcomes are achievable for children living with CAH and other chronic health conditions in resource-poor settings. CLAN's strategic framework for action offers a model for those committed to #LeaveNoChildBehind. The read this paper in full, use the following link - https://www.mdpi.com/2409-515X/6/4/76/htm



MDPI

check for updates

#### Article We All Have a Role to Play: Redressing Inequities for Children Living with CAH and Other Chronic Health **Conditions of Childhood in Resource-Poor Settings**

Kate Armstrong <sup>1,2,4</sup><sup>(0)</sup>, Alain Benedict Yap <sup>3</sup>, Sioksoan Chan-Cua <sup>4</sup>, Maria E. Craig <sup>5,6</sup><sup>(0)</sup>, Catherine Cole <sup>1</sup>, Vu Chi Dung <sup>7</sup>, Joseph Hansen <sup>1</sup>, Mohsina Ibrahim <sup>8</sup>, Hassana Nadeem <sup>8</sup>, Aman Pulungan <sup>9</sup>, Jamal Raza <sup>8</sup>, Agustini Utari <sup>10</sup><sup>(0)</sup> and Paul Ward <sup>20</sup>

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**COVID-19 INFOGRAPHICS AND** 

### RESOURCES

The global COVID-19 pandemic is perhaps the most widespread and disastrous public health crisis of the 21st century. Misinformation is often disseminated, in a time already plagued by uncertainty and anxiety. CLAN recognises the importance of accessing comprehensible, reliable information, as a measure to redress the damage of misinformation. Moreover, CLAN understands the disproportionate impact of the current climate upon individuals in resource-poor settings, specifically children living with NCDs, and their families.

CLAN has worked to produce a valuable resource bank in conjunction with understandable infographics to assist the digestion of the vast array of information being received regarding COVID-19.

The infographics developed cover 4 primary areas: COVID-19 general information; COVID-19 and children; COVID-19 and at-risk communities, and; Long COVID.

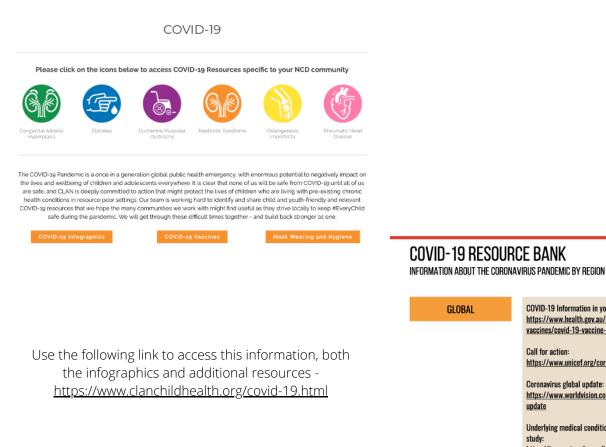
Moreover, resources have been compiled in relation to region, NCD and 2 general categories. The resources are identifiable by:

·General categories – Mask wearing & personal hygiene.

Region – Global, Australia, Europe, Fiji, Indonesia, Pakistan, Papua New Guinea, South Asia & USA.

NCD – Congenital Adrenal Hyperplasia (CAH), Diabetes, Duchenne Muscular Dystrophy (DMD), Nephrotic Syndrome (NS), Osteogenesis Imperfecta (OI), and Rheumatic Heart Disease (RHD).

Below is just a snippet of this information available on CLAN's newly updated website:





GLOBAL

COVID-19 Information in your language: https://www.health.gov.au/initiatives-and-programs/covid-19vaccines/covid-19-vaccine-information-in-your-language

Call for action: https://www.unicef.org/coronavirus/agenda-for-action

Coronavirus global update: https://www.worldvision.com.au/donate/help-children/coronavirusupdate

Underlying medical conditions in children and COVID-19 - detailed study

https://jamanetwork.com/journals/jamanetworkopen/fullarticle/27807



# **COVID-19 INFOGRAPHICS AND** RESOURCES

# COVID-19: GENERAL INFORMATION



#### WHAT IS COVID-19?

Coronaviruses are a large family of viruses that cause respiratory infections. These can range from the common cold to more serious diseases. COVID-19 is a disease caused by a form of coronavirus.

### SYMPTOMS

Symptoms can include: Fever Coughing Sore throat Shortness of breath Runny nose Acute blocked nose Headache Joint or muscle pain Nausea

If you are experiencing these symptoms, you are urged to get tested to protect yourself and others.

### Prevention & Protection

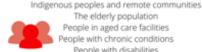
#### Hands, face, space, fresh air

Wash your hands regularly Cover your face with a mask

Leave space between yourself and others (1.5 metres) Ensure that you are in well-ventilated spaces with fresh air

#### At Risk Communities

Certain populations are more at risk than others. These include:



The elderly population People in aged care facilities People with chronic conditions People with disabilities



clinics, and it is important to understand your country's vaccination plan. This can be done by accessing trustworthy government sources.

SARS-CoV-2 transmission occurs through direct and indirect contact. distances as aerosols. Wear a mask and help stop the spread.

about COVID-19 puts lives at risk. It is a mited to UNICEF & WHO. Resources and including but not be available through gove



Caring & Living As Neighbours

# COVID A CHIINR

It is proven that children are able to contract and transmit the COVID-19 virus. It's important to understand the facts.

1,562,000 children globally have lost a primary caregiver to COVID-19 Hills, et al., 2021

Of 12-17-year-olds hospitalised by COVID: 1 in 3 ended up in ICU 1 in 20 needed a ventilator.

From August 2020 to August 2021, there have been 45.794 children admitted to hospital with

COVID-19 in the US

COVID-19 and Children's Mental Health:



countries imposed countrywide school closures, affecting more than B children and youth.

bout COVID-19 puts lives at risk. It is always important to get infor ted to UNICEF & WHO. Resources and information will also be av arces, including but not

<¢⊄lan Caring & Living As Neighbours



# COVID-19 INFOGRAPHICS AND Resources

### THE IMPACT OF COVID-19 ON AT RISK CHILDREN & COMMUNITIES

#### COVID-19 and POVERTY



40% OF THE WORLD'S POPULATION LACK ACCESS TO BASIC HAND WASHING FACILITIES AT HOME.

1.8 BILLION CHILDREN LIVE IN THE 104 COUNTRIES WHERE VIOLENCE PREVENTION AND RESPONSE SERVICES HAVE BEEN DISBUPTED DUE TO OVID-19.

10 MILLION MORE YOUNG GIRLS ARE AT RISK OF BECOMING Child Brides due to the pandemic.

#### Because COVID-19 has reduced children's access to basic healthcare:

80 million children under 1, in 68 countries could miss out on lifesaving vaccines. wHo 2020

94 million children are at risk of missing measles vaccines. WHO 2020

An additional 124,000 children are risk of contracting HIV if prevention services continue to be disrupted, wHO 3838

32% of children showing signs of pneumonia are not taken to healthcare providers. UNICE 2021

There is clear evidence that people with diabetes are at higher risk of serious illness if they get COVID-19. Diabetes Australia, 2021

Hospitalisation rates for children with type 2 diabetes rose sharply during the pandemic.

#### **COVID-19 and NUTRITION**

An additional 6-7 million children under 5 may have suffered from wasting or acute malnutrition in 2020.

370 million children may have missed nutritious school meals.



ILDREN - 463

AT LEAST 1 IN 3 OF THE

UNABLE TO ACCESS

REMOTE LEARNING WHE COVID-19 SHUTTERED THEIR SCHOOLS.

MILLION CO

\$581

### COVID-19 and EDUCATION

"Well over a year into the COVID-19 pandemic, more than 900M children are still affected by full or partial school closures, and many may never return to school. It's an education crisis which threatens the future of a generation" -UNICEF's Education Chief, Robert G lenkins

SCHOOLS FOR MORE THAN 168 MILLION CHILDREN COMPLETELY CLOSED FOR Almost an extire year Due to covid-19 Lockdowns.



Msinformation about COVID-19 puts lives at risk, it is always important to get information from trustworthy sources, including but not limited to UNICEF & WHO. Resources and information will also be available through government sources.

For more information, visit, https://www.unicof.org/ https://titus.unicof.org/co.ed/ TH-and-chill https://titus.unicof.org/co.ed/ TH-and-chill



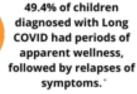
### #LONGCOVID

Post-COVID19 syndrome, more commonly known as *Long COVID*, is an array of symptoms that persist after a bout of the disease.

While it has been studied and observed in adults, Long COVID is becoming increasingly diagnosed in children.

> 7-8% of children and adolescents who are diagnosed with COVID-19 will experience persistent symptoms lasting at least 3 months (Long COVID).









### THE SYMPTOMS OF LONG COVID

Fatigue Breathing difficulty Heart palpitations Headaches Muscle and joint pain Dizziness Fever Fatigue Brain fog Hypersomnia

94.9% of children diagnosed with Long COVID had at least 4 of the above symptoms.



Children who experienced Long COVID had persisting symptoms for a mean of 8.2 months

\*Facts retrieved from: Buonsense, D. et al., (2021). Clinical Characteristics. Activity Lavets and Mental Health Problems in Children with Long COVID: A Survey of 510 Children. Preprints. DOI 10.2094/apreprints/202103.0271.v1

Misinformation about CDVD-19 puts lives at risk. It is always important to get information from trustworthy sources, including but not limited to UNICEF & WHO. Resources and information will also be available through government sources.

For more information, visit: https://www.longcovidkids.org/ Caring & Living As Neighbours





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.







# **FINANCIAL INFORMATION**



### CLAN (CARING AND LIVING AS NEIGHBOURS) INCORPORATED

ABN 30 897 322 928

### **FINANCIAL REPORT**

FOR THE YEAR ENDED 30 JUNE 2021

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

### CONTENTS

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

### **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 2021.

#### **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 Angie Middlehurst Dr Maria Craig

#### **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 \$11,010.

#### **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** 

31 August 2021

# 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 committee 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 Living As Neighbours) Incorporated for the year ended 30 June 2021, I declare that, to the best of my knowledge and belief, there have been no contraventions of:

- i. 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

Way Kr

PARTNER: W.I. RINKIN

NEWCASTLE

31 August 2021

## **INCOME STATEMENT**

## FOR THE YEAR ENDED 30 JUNE 2021

|  | 2021<br>\$    | 2020<br>\$           |
|--|---------------|----------------------|
| INCOME   |               |                      |
| Donations and gifts:<br>Monetary<br>- Corporate donations<br>- Personal donations  | -<br>7,139.65 | 6,000.00<br>1,550.00 |
| Non-monetary   | -             | -                    |
| Bequests and legacies  | -             | -                    |
| Grants:<br>Department of Foreign Affairs & Trade   | -             | -                    |
| Other Australian Grants<br>- Diabetes NSW  | 48,114.94     | 54,157.82            |
| Overseas Grants  | -             | -                    |
| Commercial Activites Income  | -             | -                    |
| Investment Income:<br>- Westpac interest   | 8.29          | 55.15                |
| Other Income:<br>- Members subscriptions   |               | 200.00               |
|  | 55,262.88     | 61,962.97            |
| LESS EXPENDITURE<br>International Aid and Development Programs Expenditure:<br>International Programs<br>Funds to International Programs |               |                      |
| - Diabetes Projects<br>- Pakistan  | 46,703.83     | 52,482.52            |
| - Uganda   | 7,457.34      | 5,105.00<br>5,539.20 |
| - Indonesia  | -             | 5,010.00             |
| - Ghana  | 3,101.24      | -                    |
| Program Support Costs  | -             | -                    |
| Community Education - Indigenous NCDs  | -             | 2,500.00             |
| Fund Raising Costs<br>- Public<br>- Government, multilateral and private   | -<br>-        | -                    |

### **INCOME STATEMENT**

### FOR THE YEAR ENDED 30 JUNE 2021

|  | Note | 2021<br>\$  | 2020<br>\$                                |
|--|------|---|---|
| Accountability and Administration<br>- Accountancy & Audit<br>- Bank charges<br>- Consultancy<br>- Insurance<br>- Printing, postage & stationery |      | 2,548.67<br>60.00<br>1,180.00<br>2,662.58<br>305.88 | 2,350.00<br>80.00<br>1,935.00<br>2,663.11 |
| - Subscriptions<br>- Teleconferences   |      | 1,757.00<br>496.23                                  | 1,750.00<br>400.08                        |
| Non-monetary expenditure   |      | -   | -   |
| Total International Aid and Development Programs Expenditure   |      | 66,272.77   | 79,814.91                                 |
| International Political or Religious Adherence Promotion Programs<br>Expenditure   |      | -   | -   |
| Domestic Program Expenditure   |      | -   | -   |
| Commercial Activities Expenditure  |      | -   | -   |
| Other Expenditure  |      | -   | -   |
| TOTAL EXPENDITURE  |      | 66,272.77   | 79,814.91                                 |
|  |      | (11,009.89)   | (17,851.94)                               |
| NET OPERATING SURPLUS (LOSS)   |      | (11,009.89)   | (17,851.94)                               |
| Other comprehensive income:  |      |   |   |
| Total other comprehensive income for the year  |      |   |   |
| Total comprehensive income (expense) for the year  |      | (11,009.89)   | (17,851.94)                               |
| Total comprehensive income (expense) attributable to members of the entity   |      | (11,009.89)   | (17,851.94)                               |

The accompanying notes form part of these financial statements.

These statements are unaudited and should be read in conjunction with the attached compilation report.

### **BALANCE SHEET**

## AS AT 30 JUNE 2021

|   | Note   | 2021<br>\$            | 2020<br>\$             |
|---|--------|-----------------------|------------------------|
| ASSETS  |        |                       |                        |
| CURRENT ASSETS  |        |                       |                        |
| Cash on hand<br>Trade and other receivables<br>Financial assets   | 2<br>3 | 22,729.35<br>741.40   | 33,769.39<br>711.25    |
| Inventories on hand   |        | -                     |                        |
| Non-current assets held for sale<br>Other current assets  | _      | <u> </u>              | -                      |
| TOTAL CURRENT ASSETS  | _      | 23,470.75             | 34,480.64              |
| NON-CURRENT ASSETS<br>Trade and other receivables   |        |                       |                        |
| Financial assets  |        | -                     | _                      |
| Non-current assets held for sale  |        | -                     | -                      |
| Property, plant and equipment   |        | -                     | -                      |
| Investment property<br>Intangible assets  |        | -                     | -                      |
| Other non-current assets  |        | -                     | -                      |
| TOTAL NON-CURRENT ASSETS  | -      | -                     | -                      |
| TOTAL ASSETS  | -      | 23,470.75             | 34,480.64              |
| LIABILITIES<br>CURRENT LIABILITIES<br>Trade and other payables<br>Borrowings<br>Current tax liabilities<br>Other financial liabilities<br>Provisions<br>Other |        | -<br>-<br>-<br>-<br>- | -<br>-<br>-<br>-       |
| TOTAL CURRENT LIABILITIES   | -      | -                     | -                      |
| NON-CURRENT LIABILITIES<br>Borrowings<br>Other financial liabilities<br>Provisions<br>Other   |        | -                     | -<br>-<br>-            |
| TOTAL NON-CURRENT LIABILITIES   | -      | -                     | -                      |
| TOTAL LIABILITIES   | -      |                       | -                      |
| NET ASSETS  | =      | 23,470.75             | 34,480.64              |
| <b>MEMBERS' FUNDS</b><br>Reserves<br>Retained earnings  | =      |                       | - 34,480.64            |
| TOTAL MEMBERS' FUNDS  | -      | 23,470.75             | 34,480.64<br>34,480.64 |
| ICIAL MEMDERS FUNDS   | =      | 23,470.75             | 34,400.04              |

### STATEMENT OF CHANGES IN EQUITY

### FOR THE YEAR ENDED 30 JUNE 2021

|   | Retained<br>Earnings | Total       |
|---|----------------------|-------------|
|   | \$                   | \$          |
| Balance at 1 July 2019  | 52,332.58            | 52,332.58   |
| Comprehensive income  |                      |             |
| 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   |
| Balance at 1 July 2020<br>Comprehensive income                            | 34,480.64            | 34,480.64   |
| Surplus (loss) for the year   | (11,009.89)          | (11,009.89) |
| Total comprehensive income for the<br>year attributable to members of the |                      |             |
| association   | (11,009.89)          | (11,009.89) |
| Balance at 30 June 2021   | 23,470.75            | 23,470.75   |
|   |                      |             |

### STATEMENT OF CASH FLOWS

## FOR THE YEAR ENDED 30 JUNE 2021

|   | Note | 2021<br>\$  | 2020<br>\$  |
|---|------|-------------|-------------|
| Cash flows from operating activities                |      |             |             |
| Receipts from customers                             |      | 55,254.59   | 61,907.82   |
| Payments to suppliers and employees                 |      | (66,302.92) | (79,524.92) |
| Interest received                                   | _    | 8.29        | 55.15       |
| Net cash provided by (used in) operating activities | 7    | (11,040.04) | (17,561.95) |
|   |      |             |             |
| Net increase (decrease) in cash held                |      | (11,040.04) | (17,561.95) |
| Cash on hand at beginning of financial year         |      | 33,769.39   | 51,331.34   |
| Cash on hand at end of financial year               | 7    | 22,729.35   | 33,769.39   |

### NOTES TO THE FINANCIAL STATEMENTS

### FOR THE YEAR ENDED 30 JUNE 2021

### 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 2021

#### (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 of 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 2021

|    |                             | 2021<br>\$ | 2020<br>\$ |
|----|-----------------------------|------------|------------|
| 2. | CASH ON HAND                |            |            |
|    | CLAN Donations              | 2,314.28   | 2,577.95   |
|    | CLAN Fund                   | 1,503.35   | 1,687.06   |
|    | CLAN Fund Interest          | 18,911.72  | 29,504.38  |
|    |                             | 22,729.35  | 33,769.39  |
| 3. | TRADE AND OTHER RECEIVABLES |            |            |

| OURICEI           |        |        |
|-------------------|--------|--------|
| Other receivables | 741.40 | 711.25 |
|                   |        |        |

### 4. 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 Coronavirus (COVID-19) pandemic 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 2021. 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.

## 5. EVENTS AFTER THE REPORTING PERIOD

As a result of the evolving nature of the COVID-19 outbreak and the rapidly evolving government policies of restrictive measures put in place to contain it, as at the date of these financial statements, the association is not in a position to reasonably estimate the financial effects of the COVID-19 outbreak on the future financial performance and financial position of the association. Other than the current disclosures, there has not been any other matter or circumstance occurring subsequent to the end of the financial year that has 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 subsequent financial periods.

### 6. 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 2021

|    |  | 2021<br>\$         | 2020<br>\$  |
|----|--|--------------------|-------------|
| 7. | CASH FLOW INFORMATION  |                    |             |
|    | (a) Reconciliation of cash<br>Cash on hand at the end of financial year as included in the<br>statement of cash flows is reconciled to the related items in the<br>balance sheet as follows: |                    |             |
|    | Cash at Bank   | 22,729.35          | 33,769.39   |
|    |  | 22,729.35          | 33,769.39   |
|    | (b) Reconciliation of cash flow from operating activities with net cu  | ırrent year profit |             |
|    | Current year profit after income tax   | (11,009.89)        | (17,851.94) |
|    | Changes in assets and liabilities:<br>(Increase)/decrease in trade & other receivables   |                    |             |
|    |  | (30.15)            | 289.99      |
|    | Net cash provided by (used in) operating activities  | (11,040.04)        | (17,561.95) |

## 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:

- present a true and fair view of the financial position of CLAN (Caring And Living As Neighbours) Incorporated as at 30 June 2021 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
- 2. 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.
- 3. 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:

Dr Kate Armstrong

President

Vice President

Catherine Cole

31 August 2021

## 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 2021 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 2021 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

Mayn Kh.

PARTNER: W.I. RINKIN

NEWCASTLE

31 August 2021

### **CERTIFICATE BY MEMBERS OF THE COMMITTEE**

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

- a. We attended the annual general meeting of the association held on .....
- b. The financial statements for the year ended 30th June, 2021 were submitted to the members of the association at its annual general meeting.

Dated: 31 August 2021

Dr Kate Armstrong

President

Vice President

**Catherine Cole** 





https://www.clanchildhealth.org/

info@clanchildhealth.org



@clanchildhealth



**CLAN Child Health** 



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