





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



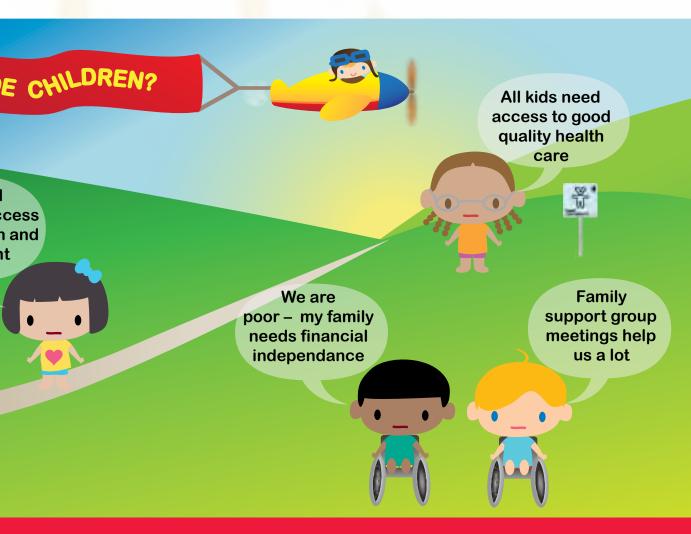
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nildren have a right to special care and assistance.

PRESIDENT'S REPORT



Dr Kate Armstrong
President and
Founder of CLAN

As CLAN reflects on a busy and action-packed 2013-14 there is much to celebrate. We've reached our ten year milestone and achieved great things with our partners and communities, and there is also much that we have learned along the way that has helped us grow stronger.

Chief amongst the take away lessons in this period has been an affirmation of the power of people. As our experience in the field of global advocacy for child health grows, we have come to fully respect the power of the children and families we seek to support, for it is repeatedly their stories, their insights and their suggestions that inform and drive change most effectively and sustainably in the countries in which we work. And it is their voices that are most powerful when they are given the opportunity to be shared on the international stage. It is their faces that have the greatest impact and capacity to raise awareness. Time and again CLAN is reminded that when we maintain the communities of children and families we work with as the visual hub of all we do, invariably we find ourselves on the right path, moving forward on a shared journey.

And perhaps it is for this reason that CLAN's 5 pillars have stood the test of time. As the core objectives of a strategic framework for action that underpins our entire community development approach to driving change, CLAN's 5 pillars arose from direct community consultation with families and young people living with Congenital Adrenal Hyperplasia (CAH) in Vietnam in 2005. The teachings of these families have stood us in good stead. What began as a child- and family-centred framework for helping children living with CAH in Vietnam has rapidly expanded across countries, conditions and cultures. In ten short years CLAN's community development approach to maximising quality of life for children living with chronic health conditions of childhood has established itself as a useful framework for action at a grassroots level in six different low-middle income countries; demonstrated its relevance across eight different chronic health conditions; reveled in diversity and resonated at a personal level with more cultural and religious minority groups than it's possible to keep track of; and fuelled and focused our own passion for global advocacy and integrating children within the Non-Communicable Disease (NCD), health and development discourse.

How can we most sustainably and altruistically share a framework for action that we believe has stood the test of time, and irreversibly changed life for thousands of children in the Asia-Pacific region for the better?

- **Partnerships** will be important. We must continue to identify strong and ethical partners with whom we can join forces to drive change. Together we are stronger!
- Action will be imperative! CLAN has always demonstrated an urgency in our desire to redress inequity
 and this must not change. Focused and collaborative strategic action around CLAN's 5 pillars will be a
 critical success factor.
- Communities of children and families must always remain central to all we do. Our connections with the world's most vulnerable must always be our lifeblood. Their suggestions, stories, voices and faces must remain the visual hub of CLAN strategic framework for action.
- **Empowerment** of our communities and young people living with chronic health conditions must remain a core value. We must move beyond unsustainable attempts to "deliver health" and focus instead on empowerment to "achieve health". Only by empowering others can we collectively achieve a shared vision.

As we approach 2015 it is a regrettable reality that the rights of too many children who are living with chronic health conditions in low- and middle-income countries are not being fulfilled or protected. Despite our achievements, since 2004 there remains much left undone. But we must not give up. There is



a Buddhist proverb that teaches "if we are facing in the right direction, all we have to do is keep on walking". Let us just add to that proverb the words... "and PACE ourselves"!

Together we are forging a path towards equity and justice for EVERY Child.

Yours sincerely Kate Armstrong

CLAN OFFICE BEARERS



Vice President
Cath Cole



Treasurer

Heidi Armstrong



Secretary Boonseng Leelarthaepin



Public Officer Valerie Foley

CLAN Honorary Member – Elisabeth Hodson



CLAN was proud to elect Dr Elisabeth Hodson as our 2013-14 Honorary Member in recognition of her outstanding contributions to improving quality of life and health outcomes for children living with Nephrotic Syndrome (NS) and Systemic Lupus Erythematosis (SLE) in Vietnam. CLAN was first introduced to Dr Hodson in late 2010 and since then she has been an invaluable member of our team, sharing her incredible expertise and experience caring for children living with NS in Australia so that children and families in Vietnam might benefit.

Dr Hodson was integral to the launch of Vietnam's first NS Club in Vietnam (February 2011) and has continued to support efforts on the ground ever since. CLAN has collaborated with partners to improve health outcomes for children presenting with NS at five major hospitals across Vietnam in recent years, and Dr Hodson has been absolutely vital to our efforts at all of these centres: the National Hospital of Pediatrics (NHP) in Hanoi; Children's Hospitals 1 and 2 in Ho Chi Minh City; Hue Central Hospital; and Thai Binh Province Hospital. Her lectures to families and health professionals alike were always well received, and her generosity of spirit advising on "difficult cases" and sharing advice during ad hoc ward rounds and clinical meetings was always especially valued. In addition to supporting CLAN's work for the NS Community in Vietnam, Dr Hodson Dr Hodson is Emeritus Consultant in Paediatric Nephrology at the Children's Hospital at Westmead in Sydney, Australia and was Head of the Department of Nephrology from 1995 to 2008. Her research interests have included CKD-Metabolic bone disease, antenatal diagnosis of urinary tract abnormalities, growth in children with chronic kidney disease and, since 2002, a cohort study of antecedents of kidney disease in Aboriginal and non-Aboriginal children and young people. Since 2000 she has been an editor for the Cochrane Collaboration's Renal Review Group, which is based in the Centre for Kidney Research at the Children's Hospital at Westmead. Dr Hodson has written and/or updated fourteen systematic reviews of randomised controlled trials of therapies for kidney disease for the Cochrane Renal Group. Dr Hodson was a member of the KDIGO international group developing guidelines for the management of Glomerulonephritis.

Thank you so much Dr Hodson for your amazing contribution to CLAN and more broadly to child health in Vietnam. �





ABOUT CLAN

What is CLAN?

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

CLAN's Vision

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

CLAN's Mission

To maximise the quality of life for children and their families who are living with chronic health conditions in resource-poor settings of the world. ��

An Innovator
Bringing
Communities
Together to Drive
Change

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

Our model is built around five pillars of action:



1: Access to Medicines and Equipment



2: Education, Research and Advocacy



3: Optimal Medical Management



4: Strong Support Groups



5: Financial Independence

CLAN's Guiding Principles

CLAN's work is premised on the following broad principles:

- a rights based approach and a love of neighbour which drives a passion for justice and equity
- building creative and trusting relationships with the people in the countries we work creating an inclusive, collaborative, flexible and responsive approach wherever possible, recognising the sum of the parts is less than the whole
- giving priority to the needs and interests of the children, families and health professionals acknowledging that grass-roots family support communities remain our visual hub, ensuring their meaningful engagement and involvement
- encouraging self help and self-reliance among beneficiaries to minimise dependency recognising the intense and overwhelming love parents have for their children and how powerful this can be when parents are empowered
- involving the people we work with to ensure the maximum extent possible in the design, implementation and evaluation of our work
- basing our work on an understanding of the history and culture of countries where we work
- supporting the economic and environmental sustainability of communities and groups
- respecting and fostering internationally recognised human rights, both socio-economic and civil-political; and, enhancing gender equity and civil society.

Probity



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

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

CLAN'S GOVERNANCE FRAMEWORK

Accountabilities

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

- ▶ IFRCRC (International Federation of Red Cross/Red Crescent Societies) Code of Conduct
- WANGO (World Association of Non Government Organisations) Code of Ethics and Conduct for NGOs
- ACFID (Australian Council For International Development) Code of Conduct
- 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
- 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 five Executive members (President, Vice President, Secretary, Treasurer and Public Officer) 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.

The CLAN Committee is organised into several distinct project-orientated sub-committees (Working Groups), and these groups are in regular communication between meetings, engaging in various projects for CLAN. CLAN Annual General Meetings are held each year, and CLAN Association Committee meetings every two months. The sub-committees report back to the CLAN Committee at meetings on the progress of their projects. 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 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.
- **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. ❖

Contact CLAN

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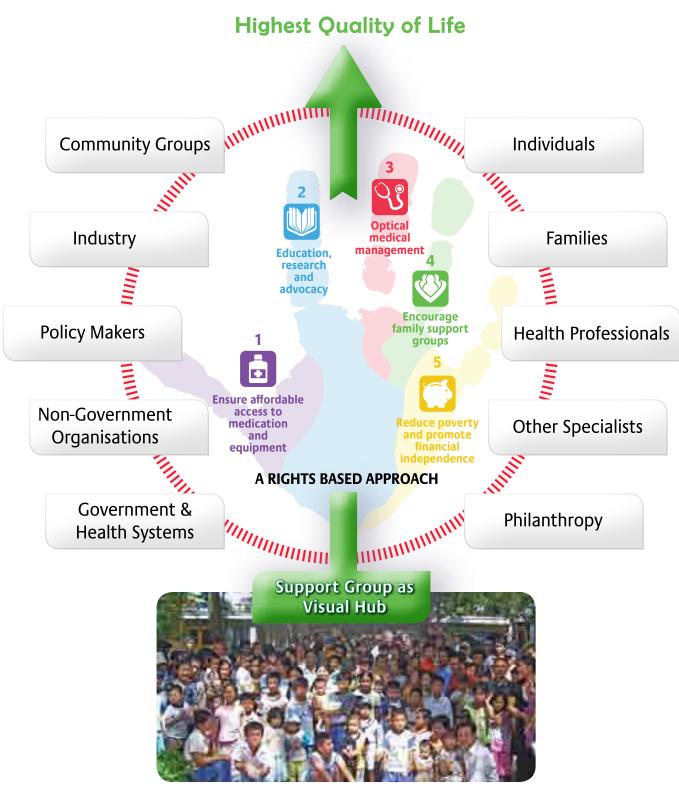
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www.facebook.com

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 with chronic health conditions. It is vital that we all strive for this, because the children and families themselves are virtually powerless to effect change without the help of their neighbours, friends, health care professionals and concerned global citizens.



A community of children, Hanoi 2007.

All children in this photo have the same chronic health condition and their families meet regularly for support.

STORIES TO INSPIRE



PILLAR ONE: Affordable Access to Medication and Equipment

Families of children who are living with chronic health conditions in resource-poor countries repeatedly tell CLAN that affordable access to essential medication and equipment is one of their greatest concerns. CLAN is committed to collaborative action that facilitates short, medium and long-term solutions to achieving sustainable change.

Launch of FOSTEO facilitates urgent access to medicines in Indonesia

Sunday, 18 November was a special day in Jakarta, with a gathering of 20 families to launch FOSTEO, a new community of children, adults and families who are living with Osteogenesis Imperfecta (OI) in Indonesia. OI is also known as "Brittle Bone Disease" and treatment with Bisphosphonates has revolutionized quality of life and health outcomes in Australia and other high-income countries. With thanks to incredible support from caring members of Indonesia's Pediatric Society (IPS) and a strong media presence at FOSTEO's inaugural meeting, immediate changes were seen to access to intravenous medication used in the treatment of OI in Indonesia.

The poster below was presented at the 53rd Annual European Society of Paediatric Endocrinology Meeting in Dublin by Drs Pulungan and Dr Pramesti in September 2014. It is a powerful example of the importance of placing children and families at the centre of all efforts to drive sustainable change for children who are living with chronic health conditions. Congratulations FOSTEO and IPS for your amazing work helping families access medicines that are saving the lives of children in Indonesia!



INTRAVENOUS ZOLEDRONIC ACID: EXPERIENCES OF TREATMENT OF CHILDREN WITH OSTEOGENESIS IMPERFECTA IN INDONESIA

Pulungan A, Zacharin M, Armstrong K, Soesanti F, Pramesti DL







BACKGROUND

It is estimated that OI occurs in 1/12,000-15,000 births.1 With approximately 240 million population in Indonesia, there should be 12.000 OI patients.2

Until September 2013, only 35 OI patiens were registered, based on the registry of Indonesian Pediatrics Society (IPS), Faculty of Medicine, University of Indonesia-Cipto Mangunkusumo Hospital (RSCM).

This enormous disconnect signifies many missed diagnoses, mortality or both.

OBJECTIVES

To raise awareness of OI and its effective treatment.

To provide ZA as an essential medicine, with consensus from IPS and guidelines for Indonesia.

METHODS

IPS working with CLAN and RCH, undertook a 2 day communitybuilding, information and education course for families of children with OI, medias, and paediatricians.

Approval was granted to treat children with OI using ZA every 4-6 months.

ZA (0.05mg/kg/dose) was administered to 21 patients [12 female], ages 0.9-18.2 years.3 Patients were observed for 24 hours. Total calcium examination was performed after 24-48 hours.

RESULTS

To date, 60 new patients with OI have been registered nationally since the education courses.

Six patients have received one dose of ZA, 10 patients received two, and five patients received three.

Well recognized mild acute phase reactions occurred in the first 24 hours after the first treatment: fever(6), fatigue(1), bone pain(1), abdominal pain(1). Asymptomatic mild reduction in serum calcium was seen in eight.

to medication and equipment

We need

affordable access



CONCLUSIONS

ZA started being used for treating OI in Indonesia since end of November 2013, right after the educational course.

Treatment has been successful to date, with minimal discomfort.

ZA has been included in the national list of essential medicines and covered by health insurance, resulting in general availability of ZA for OI treatment in Indonesia since January 2014.

It is anticipated that ongoing OI community building and dissemination of patient information throughout Indonesia will raise public awareness and result in larger numbers of affected individuals seeking treatment, further improving quality of life and reducing morbidity.

References

- National Institutes of Health and Osteogenesis Imperfecta Foundation. Guide to osteogenesis imperfecta for pediatricians and family practice physicians. Bethesda Maryland: National Institutes of Health; 2007.
- Institutes of Health; 2007.

 2. Penduduk Indonesia Menurut Provinsi 1971, 1980, 1990, 1995, 2000, dan 2010 [Internet]. Indonesia: Badan Pusat Statistik Republik Indonesia; 2012 [cited 2014 June 6] Avaliable from: http://www.bps.go.ld/tab_sub/view.php?tabe=18id_subyke=12
- Brown JJ, Zacharin MR. Safety and efficacy of intravenous zoledronic acid in paediatric osteoporosis. J Pediatr Endocrinol Metab. 2009 Jan;22(1):55-63.

ADVOCACY INSPIRED BY GRASSROOTS WORK



PILLAR TWO: Education, Research and Advocacy

Information is power. Families of children with chronic health conditions in resource poor countries consistently request help with education (not just for the children and themselves, but also for health professionals, policy makers and broader national and international communities), research and advocacy.

Australian Embassy in Hanoi supports education and training for Vietnam's DMD Community Duchenne Muscular Dystrophy (DMD) is a disorder of the muscles that results in progressive muscle degeneration and weakness. In 2012 when CLAN was first asked by the National Hospital of Pediatrics (NHP) in Hanoi to help establish a DMD support group for the hundreds of boys under their care, we could not have predicted the lasting impact of empowering young people to drive sustainable change in their own communities.

As a result of the dedication of Vietnam's DMD Club leaders, local health professionals and international partners, the DMD community in Vietnam has gone from strength-to-strength. Club membership has increased to around 200 families nationally and DMD support groups now convene in Hanoi, Hoc Chi Minh City and Hue. In 2014 a focus on developing educational activities for health professionals and families across Vietnam is helping the DMD Community grow in confidence. In this regard CLAN is extremely grateful to the Australian Embassy in Hanoi for a recent Development Aid Project (DAP)



Vietnam's DMD Club President Mr Doan Nguyen Xuan presents a gift to Ambassador Borrowman of the Australian Embassy in Hanoi

grant that enabled the local DMD Community, CLAN, C3 Vietnam and health professionals from Children's Hospital Westmead (CHW) in Sydney, Australia to collaborate on the development of educational videos and other materials and support for families.

Celebrating IDPwD 2013 in Hanoi

International Day of People with Disability (IDPwD) is a United Nations sanctioned day, held on 3 December every year, that aims to promote an understanding of people with disability and encourage support for their dignity, rights and well-being. CLAN was so very proud to celebrate IDPwD 2013 with local organizations supporting children and young adults who are living with disability in Vietnam. Our sincere thanks to: Vietnam DMD, OI, CAH Clubs; Australian Charity for Children of Vietnam

(ACCV); ACDC; Australian Embassy in Vietnam and the Vietnam Autism Network in Ha Noi. Vietnam.

We need more education, research and advocacy

On 1 December 2013 in Hanoi children and families had the opportunity to meet and share with each other, letting everyone know that they are not alone. At the event, CLAN's strategic framework for action was discussed with the families, and the importance of collaborations that engage many partners so that disability communities can grow stronger and ultimately help themselves and help their children.

Three inspiring young people who are representatives of disability communities in Vietnam (Osteogenesis Imperfecta, Duchenne Muscular Dystrophy and blind communities) shared their experience living with disability and how they find the strength to accept their reality and achieve their full potential in life. At the end of the day families wrote down their dreams and paper slips which were attached to balloons and released into the sky. As the balloons took the families' dreams to the sky everyone celebrated... Let's all work together to help make their dreams come true!



GLOBAL ADVOCACY



PILLAR TWO: Education, Research and Advocacy

A Focus on Advocacy: NCD Child is leading the way to a world in which children, adolescents, and youth are included on the global non-communicable disease agenda.

CLAN's Role of Secretariat of NCD Child in 2013-14



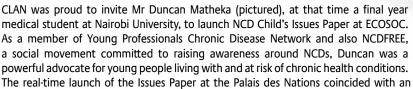
NCD Child is a coalition of organisations and individuals that emerged from the Child-focused Working Group (CFWG) of the NCD Alliance. NCD Child was launched to provide a platform for ongoing advocacy by CLAN and we were honoured to serve as the coalition's inaugural Secretariat. In record time, NCD Child has established itself as a voice for the rights of children, adolescents and youth at risk of, living with and affected by NCDs through the use of social media and broader participation in the global health and development discourse. NCD Child focuses almost exclusively on issues related to NCDs, children, adolescents and youth. There are no competing initiatives and in fact NCD Child fills a genuine gap in the NCD arena in this regard. CLAN established NCD Child to contribute messaging, advocacy, and networking that compliments the actions of other civil society and partnering organisations within the broader NCD discourse and thereby builds the capacity of existing communities to work in this space as well.

As Secretariat, CLAN determined that NCD Child would advocate for effective strategies to integrate children, adolescents, and youth on the broader global health and development agenda. Under CLAN's leadership, NCD Child promoted discussion, policies and programs that encompass:

- Considerations of child-specific issues of NCD related premature mortality, morbidity, and disability
- A life-course and rights-based approach to policy and programs
- Actions on the social determinants of health
- Empowering and engaging young people, especially those living with NCDs to become meaningfully involved in the global discourse on NCDs and to become agents of change within their communities
- Creating a knowledge-sharing platform for the exchange of ideas and collaborative projects
- Engaging multi-sectoral partners, fostering partnerships and strengthening communication channels.

The specificity of the strategies and activities that CLAN focused on whilst Secretariat of NCD Child allowed for a focused approach and clear messaging. In particular, CLAN identified three key strategic activities: an ABC approach of advocacy, building community and collaboration.

July 2013 ECOSOC Annual Ministerial Review, Geneva The theme of the 2013 ECOSOC Annual Ministerial Review was Science, technology and innovation, and the potential of culture, for promoting sustainable development and achieving the MDGs. NCD Child welcomed the opportunity to launch an Issues Paper at the ITU-IFPMA Ministerial Roundtable Breakfast, Mobile Worlds, Mobile Actions – mHealth: The Opportunity for NCDs – Palais des Nations, Geneva, 2 July 2013.





online launch of the Issues Paper. Titled Young People and NCDs: Harnessing the Culture of Technology, this paper provided a set of specific recommendations for Member States to harness the culture of technology in young people.

Young People, NCDs and Disability: Maximising Capacity Accross the Lifecourse CLAN was proud to lead the development of an Issues Paper on behalf of NCD Child to coincide with the September 2013 United Nations General Assembly High-Level Meeting (UNHLM) on Disability and Development. Addressing the overarching theme of the UNHLM (The Way Forward: a Disability Inclusive Development Agenda Towards 2015 and Beyond), the paper made a case for placing all young people, including those living with or at risk of disability, at the centre of development to maximise capacity across the life-course. \diamondsuit



NCD CHILD CONFERENCE 2014



PILLAR TWO: Education, Research and Advocacy

A Focus on Advocacy: NCD Child is leading the way to a world in which children, adolescents, and youth are included on the global non-communicable disease agenda.

NCD Child Doing What Needs to be Done The NCD Child: Doing What Needs to Be Done Conference was held at the Hyatt Regency Hotel in Port-of-Spain, Trinidad and Tobago over two days – 20 March to 21 March 2014 and was kindly hosted by the Ministry of Health of the Republic of Trinidad and Tobago.

The 2014 NCD Child conference aimed to create a platform for interaction, knowledge exchange, and a priority focus on the needs of children and adolescents within the context of grassroots NCD action and global advocacy efforts around the post 2015 agenda and Millennium Development Goal (MDG) review.

With over 200 delegates from more than 20 countries attending in person – and the same number of participants again joining proceedings online via webinar! – this conference brought together an enormous range of organisations, sectors and stakeholders as one community, united by a shared passion for the meaningful integration of children, adolescents and a life-course approach within the international Non-Communicable Disease (NCD), health and development discourse.

This second International NCD Child Conference in Port-of-Spain conference would not have been possible without the vision and generosity of spirit demonstrated by the Honorable Minister of Health for Trinidad and Tobago, Dr Fuad Khan. The Caribbean region is highly regarded internationally for its leadership in the NCD space, and indeed Trinidad is the birthplace of the historic Declaration of Port-of-Spain: Uniting to Stop the Epidemic of Chronic NCDs (September 2007). The conference saw the NCD Child Community united as a cohesive, collaborative, global coalition; connecting beyond sectors and special interests to share ideas, support and challenge the status quo; to re-trace our elders' footsteps in many regards, and yet simultaneously break beyond, tread new ground and consider what a life-course approach to NCDs might meaningfully look like in the post 2015 agenda if we were bold and brave enough to embrace it to our fullest capacity.

There were encouraging signs for the pilgrims present, most notably with the inspirational support received from His and Her Excellency of Trinidad and Tobago highlighting the value now being placed by some of the most powerful minds in the Caribbean and beyond on ensuring urgent action around NCDs protects and promotes the health and well-being of society's youngest and most vulnerable members. �

The Australian High Commission hosts a Reception for NCD Child



As an Australian NGO, CLAN was particularly grateful to the Australian High Commission for supporting the Conference. On 18 March 2014, ahead of the official opening of the conference, the Australian High Commissioner, His Excellency Ross Tysoe and Her Excellency Ms Helen Saunderson (pictured left) graciously hosted an event in support of NCD Child. The Australian High Commissioner's commitment to promoting the health and well-being of young people worldwide was clearly displayed through his support of NCD Child, as well as in his partnership with the Healthy Caribbean Coalition to prevent cervical cancer in the region. In addition, the Australian High Commissioner was a key speaker on Day 1 of the NCD Child conference, speaking on Australia's commitment to fight tobacco and NCDs, making evident the role of Australia in promoting a life-course approach to NCDs both at home and abroad.





UNICEF Technical
Meeting — Facts for
Life Chapter on NCDs
and Healthy Living

Given the growing challenge and burden of NCDs, there has been an increasing focus and momentum from UN agency partners to address them in their work, starting from the UN Political Declaration on NCDs (2011) and more recently the UN Interagency Task Force on NCDs (October 2013). In fact, one of the emerging initiatives involves a commitment from UNICEF to lead the development of a chapter on NCDs in the UN Facts for Life (FFL) Communication for Development tool as an effort to scale up a proven health promotion and primary prevention approaches initiatives for NCDs.

On 19 March 2014, UNICEF and NCD Child met in Port-of-Spain for a one-day technical review meeting of the Zero Draft chapter the day prior to the commencement of the NCD Child Conference. The meeting was well attended by NCD experts and UN partners to review and make recommendations on the content for the draft chapter as well as for its roll out and related advocacy. A working group and youth engagement group was formed and has since supported core consultancy moving forward on the development of content.

UNICEF Partnership Agreement with NCD Child As Secretariat of NCD Child, CLAN was proud to oversee NCD Child engage in a formal Programme Cooperation Agreement (PCA) with UNICEF. This partnership will support joint actions that place children, adolescents and young people at risk or living with non-communicable disease (NCDs) as key priorities in the global NCD response. The initial one-year agreement included the development of the chapter on NCDs and healthy living for Facts for Life.

Sir George Alleyne, Chancellor of the University of the West Indies, stated "Facts for Life is one of UNICEF's flagship publications, so it is heartening to see is include NCDs in the series – it will provide a tool for advocacy about the importance of NCDs; what the global public should know and more importantly what they can do"

The President's Office of Trinidad and Tobago is clearly committed to ensuring young people are empowered and meaningfully involved in NCD action. Her Excellency, Reema Carmona, gave the Opening Address and His Excellency Anthony Thomas Aquinas Carmona S C invited a cohort of Presidential Youth Representatives to attend. Together, the highest office of Trinidad and Tobago inspired everyone in attendance that longterm, sustainable change is not only possible but also achievable when we all play our own role.









STORIES TO INSPIRE



PILLAR THREE: Optimising Medical Management

If children living with chronic health conditions in resource poor countries are to achieve equitable health outcomes, on par with their neighbours' children in higher income countries, they must have access to optimal medical management. Families always request a focus on prevention so that their own and other children do not suffer unnecessarily, and appreciate a holistic approach to health.

Vietnam's NS Community Delivering Optimal Medical Management Chronic Kidney Disease is an enormous issue for children in Vietnam. It is estimated that there are currently around 3,000 children with Nephrotic Syndrome (NS) in Vietnam. When CLAN was first approached to work with NS communities, morbidity associated with NS in Vietnam was much higher than in wealthier countries, and renal departments and health professionals in Vietnamese paediatric hospitals were overwhelmed with the high numbers of children suffering serious complications from NS and repeat admissions for acute relapses.

Since NS Clubs were first started in Vietnam in 2011, much has changed. Medications are now available on the national insurance scheme: more children with NS are attending school; more children are in remission (35.4% in 2012 versus 53.0% in 2013); and admission rates to hospital have dropped markedly. In North Vietnam transfers of children with NS to the National Hospital of Pediatrics in Hanoi for treatment from one rural centre dropped from 24.6% in 2012 to10.0% in 2013. Empowerment of parents has also played a role, and a survey of families at a recent CLAN NS Club found that over 90.0% of families now test their children's urine for



protein at home, compared to just 10.0% of families testing at home three years ago.

A major key to the success of CLAN NS communities in positively impacting medical management of NS has been the delivery of two complementary components in each CLAN-collaborating centre: continuing medical education (CME) sessions conducted for the benefit of paediatric physicians; and club meetings for families of children with nephrotic diseases. The Club meetings are both an invaluable social support for families as well as an essential source of medical information on how to best manage their child's condition. It is also proving to be a key platform to debunk common myths and misconceptions such as the need to keep a child with NS away from school. The overwhelming benefit of Club meetings for families is that parents are active participants in the provision of their children's healthcare and supporting their children to reach their full potential as members of their own communities.

Partnering with NephCure Kidney International to Help Children in Vietnam Fostering closer linkages between health professionals and families is proving to be mutually beneficial. Collaborative links with other international NGOs can make a huge difference, and an example of this is the support the Vietnamese NS Community has received from the US-based charitable organisation NephCure Kidney International so that children in Vietnam may benefit



from international efforts to find a cure for Nephrotic Syndrome. Following a visit to Vietnam in 2014 two young medical students, Azadeh Issapour and David Cisewski (participants in the Global Health Travel Program at the Albert Einstein College of Medicine, NY) wrote: "Those children, their families and the healthcare teams taking care of them are now a part of the force that motivates us to work to our fullest potential and become effective physicians - the kind of healer that is capable of advocating for patients and making global changes to healthcare."

Health Professionals Get Together to Discuss OI Coinciding with CLAN's support of the launch of Indonesia's inaugural Osteogenesis Imperfecta (OI) Club in Jakarta in November 2013, we were inspired by efforts to promote excellence in the field of pediatric endocrinology and the management of OI across the archipelago. Combining Family Support Group meetings with Continuing Medical Education (CME) updates for health professionals is a core focus for CLAN, and we were delighted to meet around 30 Indonesian health professionals from a range of distant islands and cities who all came together on Sunday 18 November for a series of detailed updates on OI. Drs Wayan, Sudung and Pulungan welcomed the many health professionals present and everyone participated enthusiastically in the sessions. The management of OI requires multidisciplinary care, so

it was fantastic to see so many different groups represented that night (orthopaedic surgery included!).

Dr Aman Pulungan gave one of the first lectures, and presented the latest insights into the burdens and challenges facing children living with OI in Indonesia. A particularly exciting development in Indonesia for the OI Community (FOSTEO) has been the development of a new patient register and data from this informed much of Dr Pulungan's talk. The new patient register is a powerful tool, generating novel information that is already informing action and driving advocacy efforts at a national and international level. Dr Pulungan spoke to the need for health insurance to support families in a practical and meaningful way and an urgent call was made for a chance to the current situation

(where congenital conditions are not covered by health insurance).

Dr Margaret Zacharin from Royal Children's Hospital

Melbourne provided a series of important updates on the medical management of OI, and facilitated an interactive question and answer time. Dr Kate Armstrong encouraged the health professionals present to continue in their important role supporting the future developments that can – and must - be collectively achieved for FOSTEO.

At the end of the educational session commitments were made by the governing Indonesian Pediatric Society's Endocrinologists to work collectively on establishing national treatment guidelines for OI in Indonesia, and aim towards presentating of 2013 Family Survey results back to FOSTEO Community members at a Wishbone Day gathering in Jakarta on 6 May 2014... This was achieved, and CLAN thanks everyone involved in supporting FOSTEO for their vital role in fast-tracking equity for this previously neglected community of children and families in Indonesia.

All kids need access to good quality health care





STORIES TO INSPIRE



PILLAR FOUR: Enouragaging Family Support Groups

Over many years CLAN has observed the power of bringing families of children who are living with the same chronic health condition together as a 'community' and working in partnership with other partners to drive sustainable change. When individuals come together as communities, great things happen!

Kenya's RHD Community Creating Strong Support Groups

Bringing a Voice to Young People with RHD in Kenya and the Promise of Sustainable Change Rheumatic Heart Disease (RHD), a chronic heart condition caused by rheumatic fever (RF), is the most common acquired heart disease in children. Today, RHD is largely a disease of low-income and disadvantaged communities with some estimates showing that three out of every 100 children and adolescents in developing countries are affected by this condition. Tragically, it is completely preventable and easily controlled by antibiotics if 'Strep' sore throats are detected and treated early. For those young people living with RHD, access to specialised facilities and care, and long-term follow-up is needed. Raising awareness and promoting a holistic approach to RHD prevention and care are essential to ensure early diagnosis and affordable access to health services so as to alleviate the burden of this preventable disease.

In March 2014, a group of students and young health professionals at the University of Nairobi brought together families of children who are living with RHD as a community working in partnership to drive sustainable change. The group has adopted the CLAN model of action, creating a strong support group with the mission of promoting a holistic approach to RHD in Kenya. The first RHD meeting brought together 11 RHD patients and their families who were provided with important information around managing their children's disease as well as the children being provided with a free diagnostic echocardiogram (heart ultrasound) that will help to track their progress over time.

The success story of the day was a 24 year old nursing student at the University of Nairobi who shared his struggle with Rheumatic Fever and eventual success. Despite being diagnosed with RF in high school, he keenly followed through with his treatment for 8eight years and as a result of regular follow-up, has not developed other complications and his last echocardiogram reveals normal heart function. Despite having to keep up with the monthly appointments, financial constraints and missing out on his favourite sport, the then 14 year old managed to pass his exams and join the University of Nairobi. He encouraged the children attending the RHD Club meeting to remind their parents to take them to the hospital for their monthly penicillin injections to prevent development of complications. Of great importance, he was an inspiration to the young people present as to what can be achieved with effective treatment and management of RHD.

Family support group meetings help us a lot



As well as helping those families present on the day, strong linkages were established at both the national and international levels cementing the importance of the Nairobi Club in driving sustainable change for children living with RHD in Kenya. This was evident in the outcomes already achieved since March including multisectoral planning to improve access to medicine; utilization of mobile phone networks to enable ongoing communication amongst families and health professionals; clarification of community priorities; and the development of strategies to strengthen existing health systems and stream-line outpatient care. ��



Strengthening Support for Children in Rural Vietnam

Supporting a Nephrotic Syndrome Club Meeting at Thai Binh Pediatric Hospital After several years supporting Nephrotic Syndrome (NS) Club Meetings at the major tertiary referral hospital in North Vietnam, the National Hospital of Pediatrics (NHP) in Hanoi, CLAN's team was thrilled on 23 June 2014 to travel to Thai Binh Province and attend the 2nd Annual NS Club meeting and support a training session for health professionals in this more rural area.

Thai Binh has a population of 1.9 million and is a three hour drive from Hanoi. Until just a few years ago was one of the poorest provinces in North Vietnam, with a majority of families from farming background (Thai Binh is well known for its rice). Thai Binh Pediatric Hospital is a 160 bed facility and was opened in 2007. It is one of around 10 stand alone pediatric hospitals in rural regions in Vietnam, and Dr Pham Thi Huong is the Head of the Nephrology Department, which cares for around 90 children with Nephrotic Syndrome. Particularly after the 2013 NS Club meeting, Thai Binh Pediatric Hospital is gradually increasing its capacity to care for children with NS locally, so staff and families alike were thrilled to have visiting international experts in the field of Nephrotic Syndrome (NS) travel to Thai Binh to support local efforts to maximize quality of life for children living with NS in this rural region.

Children living with chronic health conditions such as NS in rural parts of low- and middle-income countries such as Vietnam face unique challenges. For instance, a show of hands amongst NS Club members indicated that no families in the Thai Binh NS Club speak English and very few use Facebook, hence finding ways to connect internationally and overcome language barriers will be an important consideration for future efforts. By contrast, around 50% of families present raised their hands to indicate they had attended the inaugural 2013 NS Club at NHP in Hanoi. More exciting still, over 70% of families indicated they now test their children's urine for protein at home following recent education,





and this is already have marked effects on health outcomes for the children! Encouraging data clearly shows that treatment outcomes have improved for children in Thai Binh from 2012 to 2013, with remission rates up (from 35.4% to 53%); transfers to NHP down (from 24.6% to 10%); only a third as many children admitted because of NS; and fewer having relapses.

Overall there was a great feel to this NS Club meeting in rural Vietnam, and the future for the NS Community in Thai Binh appears very bright. Thai Binh Pediatric Hospital now has 2 Clubs for chronic health conditions of childhood (Asthma and NS), with plans to expand in 2015 to Epilepsy and Autism. CLAN is excited about these recent developments for families and children in Thai Binh. CLAN would like to sincerely thank the following national and international experts for travelling to Thai Binh, and sharing their time and experience so generously with the NS Community in Vietnam: Dr Nguyen Thu Huong (Head of Nephrology Department at NHP); Dr Elisabeth Hodson (Paediatric Nephrologist, The Children's Hospital at Westmead, Australia); Mr Henry Brehm (Executive Director, The NephCure Foundation, USA); and Ms Azadeh Issapour and Mr David Cisewski (Medical Students from Albert Einstein College of Medicine). Especial thanks must also go to NephCure International for their very generous support of the 2014 NS Club meetings of Vietnam – it is incredible what can be achieved when the global NS Community connects and works together!







STORIES TO INSPIRE



PILLAR FIVE: Reducing Poverty and Promoting Financial Independence

Financial burdens are overwhelmingly one of the greatest worries facing the families of children with chronic health conditions in resource-poor countries. CLAN is committed to working in partnership with NCD Communities to open the doors of opportunity that lead to freedom from poverty and the power of financial independence.

Indonesia's OI Community Supporting Financial Independence

For One Young
Girl, the Doors of
Opportunity that
Lead to Freedom
and Financial
Independence have
been Opened

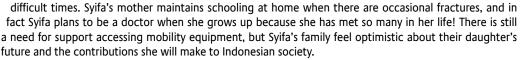
Osteogenesis Imperfecta (OI) is a genetic bone problem where the bones are not made properly and as such fracture very easily. Fractures can occur spontaneously or after minimal trauma. Children with OI can have literally hundreds of fractures during their life. Recurrent fractures result in pain, limb deformity, spine curvature, inability to walk and reduced life span. Children living with OI may experience limited educational and job opportunities, placing a major financial burden on families and the community as a whole. Yet when barriers are reduced and opportunities are created for education and employment, young people living with OI can contribute to economic and social development in their own countries.

Syifa is a young Indonesian girl living with OI. When Syifa was first taken to a doctor as an infant, the doctor told her mother to accept that Syifa would die in three months. Instead her mother sought a second opinion and Syifa was diagnosed with OI. Thanks to receiving access to life-saving medicines, treatment was started when she was seven months old to strengthen Syifa's bones. As a result, she showed dramatic improvements in her growth, development and quality of life.

As a teacher, Syifa's mother knew the importance of her daughter receiving an education. With the Indonesian government supporting a disability-inclusive approach to education, Syifa's school experience has been very positive, and teachers and peers alike ensure Syifa is welcomed warmly and supported through



We are poor – my family needs financial independance





In 2013 Indonesian health professionals and OI families joined in partnership with CLAN and the International OI Community (Wishbone Day) to establish the first Indonesian OI Community (now called FOSTEO). After only a year, a number of milestones at the national level have been achieved. These include addition of essential OI medicines to the Indonesian national health insurance scheme; development of a national register (with a dramatic increase in known number of persons living with OI in Indonesia – from 25 to 100+ within the first three months!) and online connections utilizing mobile phones and WhatsApp to foster a strong sense of community connectedness that reduces feelings of isolation, shame, fear and powerlessness. FOSTEO is ensuring children diagnosed with OI in Indonesia in future are fast-tracked to enjoy the highest quality of care and health outcomes possible.

Meet Thuong! An Artist, Leader and Entrepreneur



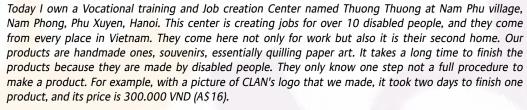
Nguyen Thi Thu Thuong is an inspirational young woman living with Osteogenesis Imperfecta in Vietnam. This is her story...

My name is Thuong, and I am a manager of Thuong Thuong Vocational Training and Job Creation Center. First of all, I would like to say thank-you to CLAN for caring about young people living with a chronic disease in Vietnam, especially those with OI (Osteogenesis Imperfecta) and DMD (Duchenne Muscular Dystrophy).

According to my mother's story about my childhood, I had a very big head, green/blue eyes and a reversed look when I was a newborn baby. I cried



and even burst into loud wails every time I was having my diaper changed. My parents were so worried, and they brought me to visit the doctor. The doctor diagnosed that I suffered from OI (Osteogenesis Imperfecta) and said my bones were brittle and easy to break. During my childhood, my bones were broken lots of time and I couldn't go to school as my peers did. Thirty years passed and I have been like a five year old child... I cannot move, cannot stand, cannot sit, but can only lie down. Though I get older it is still easy for my bones to break if I am unlucky and get an impact of any sort. But this is not a reason to give up my life – it inspires me to build a beautiful and meaningful life for me and other people living with disability.



I was so glad when I heard the good news from Mr Doan – President of Vietnam's DMD Organisation – that he will take order for us to make products. To be a founder of the Center, I am looking for purchase orders to create jobs and monthly income for members as well as expenditure to cover their daily lives. Truly I hope that CLAN and organizations give us opportunities to bring our products to all over the world or projects to support us, or by multimedia to advertise us, help us to contact with customers who are in demand of our products. This really help us to improve our lives and believe in our jobs that requires detailed efforts and carefulness.

We have a website at www.thuongthuong.net and you can order online, or email me via thuongthuong.net@gmail.com

At present, the Center has vocational positions supporting young people living with DMD, OI and other conditions where individuals can manage personal hygiene independently. As I know that there are many people who suffer in OI as me, they always desire to work to get a better and meaningful life but their disabilities are so serious that they cannot manage personal hygiene independently, so we would

like to identify a sponsor from society who might contribute this amount so we can hire a personal assistant to clean and wash for them, in order to make them confident to work in our center or in their own home, so that they will be more empowered and self controlled in making decisions about their lives. It is my wish to continue working well and hard to support disabled people in Vietnam.

To conclude, I would like to say, "Please trust us and give us a chance to work. We are down but not out!".

I'm looking forward to seeing you someday. Thank you so much for reading this! �





CLAN FINANCIALS

Committee's Report for the Year Ended 30 June 2014

Your committee members submit the financial accounts of the CLAN (Caring And Living As Neighbours) Incorporated for the financial year ended 30 June 2014.

Committee Members

Dr Kate Armstrong B Med, DCH, MPH

Heidi Armstrong BSc, LLB

Catherine Cole JP

Valerie Foley

Dr Boonseng Leelarthaepin PhD, BSc, Dip Nut Diet

Robert Armstrong

Dr Sue Ditchfield

Amy Eussen

Laura Healy LLB, BMus, LLM

Michelle J Konheiser

Kelly Leight

Dr Yen-Thanh Mac MD

Peter Watt

Dr Andrea Zalan

James Willett MA

Sandy Harwood Dip Applied Science

Principal Activities

The principal activities of the Association during the financial year were: Charitable organisation.

Significant Changes

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

Operating Result

The profit from ordinary activities after providing for income tax amounted to:

Year ended 30 June 2014

Year ended Prev Year End

(\$110,887)

\$89,505

Signed in accordance with a resolution of the Members of the Committee:

Dr Kate Armstrong Committee Member Heidi Armstrong Treasurer

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Independent Auditor's Report to the Members for the Year Ended 30 June 2014

Report on the Financial Report

We have audited the accompanying financial report, being a special purpose financial report, of CLAN (Caring & Living As Neighbours) Incorporated (the Association), which comprises the Statement by Members of the Committee, Income and Expenditure Statement, Balance Sheet, notes comprising a summary of significant accounting policies and other explanatory notes for the financial year ended 30 June 2013.

Committee's Responsibility for the Financial Report

The Committee of CLAN (Caring & Living As Neighbours) Incorporated are responsible for the preparation of the financial report and have determined that the basis of preparation described in Note 1, is appropriate to meet the requirements of the Associations Incorporation Act of New South Wales 2009 and is appropriate to meet the needs of the members. The Committee's responsibilities also includes such internal control as the Committee determine is necessary to enable the preparation of a financial report that is free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on the financial report based on our audit. We have conducted our audit in accordance with Australian Auditing Standards. Those Standards require that we comply with relevant ethical requirements relating to audit engagements and plan and perform the audit to obtain reasonable assurance whether the financial report is free from material misstatement. An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial report. The procedures selected depend on the auditor's judgement, including the assessment of the risks of material misstatement of the financial report, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the Association's preparation of the financial report that gives a true and fair view, 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. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the Committee, as well as evaluating the overall presentation of the financial report. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Basis for Qualification of Auditor's Opinion

It is not practical for the organisation to maintain an effective system of internal control over donations and fund raising activities until their initial entry in the accounting records, our audit in relation to donations and fund raising was limited to amounts recorded and the records provided. In addition it is not practical for the organisation to maintain an effective system of internal control over costs relating to travel in foreign countries where activities are undertaken due to the nature of the records in these countries until their initial entry in the accounting records, our audit in relation to these costs was limited to amounts recorded and the records provided.

Qualified Auditor's Opinion

In our opinion, except for the effects of such adjustments, if any, as might have been determined to be necessary had the limitation discussed in the qualification paragraph not existed the financial report of the CLAN (Caring & Living As Neighbours) Incorporated presents fairly, the financial position of CLAN (Caring & Living As Neighbours) Incorporated as at 30 June 2013 and its financial performance for the year then ended in accordance with the accounting policies described in Note 1 to the financial statements, and the Associations Incorporation Act of New South Wales 2009.

Basis of Accounting

Without modifying our opinion, 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 Associations Incorporation Act of New South Wales 2009. As a result, the financial report may not be suitable for another purpose.

Blair Andrew Powell

Barrell

Registered Company Auditor Wishart Powell Pty Limited 1/456 The Esplanade WARNERS BAY NSW 2282

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Income and Expenditure Statements for the Year Ended 30 June 2014

	2014 (\$)	2013 (\$)		20	14 (\$)	2013 (\$)
INCOME			CURRENT ASSETS			
DONATIONS & GIFTS			Cash & cash equivalents	2	18,127	133,030
» Monetary	32,124	30,592	Trade & other receivables		4,182	1,514
» Non-monetary	-	-	Total Current Assets		22,309	134,544
» Grants	124,240	185,677	NON CURRENT ACCETS			
» AusAID	-	-	NON-CURRENT ASSETS			
OTHER INCOME	2,289	10,539	Property, plant & equipment	3	1,567	219
Total Income	158,653	227,108	Total Non-Current Assets Total Assets		1,567 23,876	219 134,763
EXPENSES			- CURRENT LIABILITIES			
INTERNATIONAL AID & DEVELOPM	MENT PROGRAMS EX	KPEDITURE	Trade and other payables-			
» International Programs	128,141	87,054	Borrowings -			
» Community education	-	-	•		-	
» Fundraising costs	-	-	Current tax liabilities-		-	
» Accountability & Administration	n 141,399	50,549	Provisions		-	-
» Non-monetary expenditure	-	-	Other		-	-
Total International Aid & Development Programs			Total Current Liabilities-			
Expenditure	269,540	137,603	NON-CURRENT LIABILITIE	ES		
Total Expenses	269,540	137,603	Borrowings -		-	
Profit from ordinary activities	(440.007)	00 505	Other financial liabilities		-	-
before income tax	(110,887)	89,505	Provisions		-	-
Income tax revenue relating to ordinary activities	-	-	Other		<u>-</u>	-
Net profit attributable to the			Total Non-Current Liabilities		-	-
association	(110,887)	89,505	Total Liabilities-		-	
Total changes in equity of the association	(110,887)	89,505	Net Assets		134,763	45,258
Opening retained profits	134,763	45,258				
Net profit attributable to the			EQUITY			
association	(110,887)	89,505	Reserves		-	-
Closing retained profits	23,876	134,763	Retained profits		23,876	134,763
			Total Members' Funds		23,876	134,763

Income and Expenditure Statements for the Year Ended 30 June 2014

NOTE 1: Summary of Significant Accounting Policies

This financial report is a special purpose financial report prepared in order to satisfy the financial reporting requirements of the ACFID Code of Conduct and the Associations Incorporations Act of New South Wales. The Committee has determined that the Association is not a reporting entity.

The financial report has been prepared on an accruals basis and is based on historical costs and does not take into account changing money values or, except where specifically stated, current valuations of non-current assets.

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

(a) Property, Plant and Equipment (PPE)

Leasehold improvements and office equipment are carried at cost less, where applicable, any accumulated depreciation.

The depreciable amount of all PPE is depreciated over the useful lives of the assets to the Association commencing from the time the asset is held ready for use.

Leasehold improvements are amortised over the shorter of either the unexpired period of the lease or the estimated useful lives of the improvements.

(b) Impairment of Assets

At the end of each reporting period, the entity reviews the carrying values of its tangible and intangible assets to determine whether there is any indication that those assets have been impaired. If such an indication exists, the recoverable amount of the asset, being the higher of the asset's fair value less costs to sell and value in use, is compared to the asset's carrying value. Any excess of the asset's carrying value over its recoverable amount is expensed to the income statement.

(c) Cash and Cash Equivalents

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

(d) Revenue and Other Income

Revenue is measured at the fair value of the consideration received or receivable after taking into account any trade discounts and volume rebates allowed. For this purpose, deferred consideration is not discounted to present values when recognising revenue.

Interest revenue is recognised using the effective interest rate method, which for floating rate financial assets is the rate inherent in the instrument. Dividend revenue is recognised when the right to receive a dividend has been established.

Grant and donation income is recognised when the entity obtains control over the funds, which is generally at the time of receipt.

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

(e) Leases

Leases of PPE, where substantially all the risks and benefits incidential to the ownership of the asset, but not the legal ownership, are transferred to the association, are classified as finance leases.

Finance leases are capitalised by recording an asset and a liability at the lower of the amounts equal to the fair value of the leased property or the present value of the minimum lease payments, including any guaranteed residential values. Lease payments are allocated between the reduction of the lease liability and lease interest expense for that period.

Leased assets are depreciated on a straight line basis over the shorter of their estimated useful lives, or the lease term. Lease payments for operating leases, where substantially all the risks and benefits remain with the lessor, are charged as expenses in the period in whey they are incurred.

(f) 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. In these circumstances, the GST is recognised as part of the cost of acquisition of the asset or as part of an item of the expense. Receivables and payables in the assets and liabilities statement are shown inclusive of GST.

Statement of Cash Flows for the Year Ended 30 June 2014

NOTE 2: Cash Assets	2014 (\$)	2013 (\$)	
Bank accounts:			
CLAN Donations	8,340	4,534	
CLAN Fund	3,369	1,051	
CLAN Fund Interest	6,418	127,446	
	18,127	133,030	
NOTE 3: Property, Plant & Equipment	2014 (\$)	2013 (\$)	
Leased plant and equipment:			
At cost	6,649	4,463	
Less: Accumulated amortisation	(5,082)	(4,244)	
	1,567	219	
	40	40	
CASH FLOW FROM OPERATING ACTIVITIES	2014 (\$)	2013 (\$)	
Receipts from customers	158,653	224,298	
Payments to suppliers and employees	(273,386)	(137,164)	
Interest received	2,016	1,628	
Net cash provided by (used in) operating activities (note 2)	(112,717)	88,762	
Purchase of plant and equipment	(2,186)	-	
Net cash (used in) investing activities	(2,186)		
Net increse (decrease) in cash held	(114,903)	88,762	
Cash at the beginning of the year	133,030	44,268	
Cash at the end of the year (note 1)	18,127	133,030	

Statement by Members of the Committee for the Year Ended 30 June 2014

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 the opinion of the Committee the Income and Expenditure Statement, Statement of Financial Position, and Notes to the Financial Statements:

- 1. Presents fairly the financial position of CLAN (Caring & Living As Neighbours) Incorporated as at 30 June 2012 and its performance for the year ended on that date.
- 2. At the date of this statement, there are reasonable grounds to believe that the Association will be able to pay its debts as and when they fall due.

This statement is made in accordance with a resolution of the Committee and is signed for and on behalf of the Committee by:

Dr Kate Armstrong

President

Heidi Armstrong

Treasurer

I, Dr Kate Armstrong of 13 Fourth Avenue, Denistone NSW; and I, Heidi Armstrong of 10 Robey Road, Coal Point NSW certify that:

- 1. We are members of the Committee of CLAN (Caring & Living As Neighbours) Incorporated.
- 2. We attended the annual general meeting of the Association held on 11 December 2013.
- 3. We are authorised by the attached resolution of the Committee to sign this certificate.
- 4. This annual statement was submitted to the members of the Association at its annual general meeting.

Or Kate Armstrong

Committee Member

Heidi Armstrong

Treasurer

WITH THANKS

Australia's CAH Community supporting Nigeria's **CAH Community**

With thanks to the generous fundraising efforts of the Marshall Family in Sydney, Australia (members of Australia's CAH Community!), CLAN was able to support the launch of a new CAH Community in Nigeria.

Special thanks must go to Prof Abiola Oduwale, Prof Ze'ev Hochberg (of the Global Pediatric and Diabetes Group) and Mrs Helen Ogunsanya for their outstanding efforts making this Club meeting possible.

The CAH Community in Nigeria faces many challenges chief amongst them are delayed diagnoses; unaffordable and unreliable access to essential medicines; barriers accessing appropriate investigations (blood samples must be sent to South Africa at great cost) and widespread poverty.

Thanks to the generosity of the CAH Community in Australia, CLAN was able to send a donation of medicines and other resources to the budding CAH Community in Nigeria. We wish them every success in their ongoing efforts to maximise quality of life for children living with CAH in Nigeria and will be sure to stay in touch! 💠







A Pie in the Face Changes Lives!

CLAN is incredibly grateful to the amazing Professor David Little (Paediatrics and Child Health with Children's Hospital Westmead and University of Sydney) who very generously committed to getting involved supporting the Osteogenesis Imperfecta (OI) and Duchenne Muscular Dystrophy (DMD) Communities of Vietnam.

An expert in the field of child health in Australia (specialising in bone health), Prof Little bravely stepped up to help CLAN raise much needed funds to support the OI and DMD Club meetings in 2014.

On 5 May in the Orthopaedic Clinic at the Children's Hospital Westmead, Prof Little went above and beyond the call of duty, agreeing to have pies thrown at his face by colleagues



and 'friends'... Let's just say there was quite a queue to donate and we are thrilled to say that A\$7, 058 was raised in total!!!

Thank you so much Prof Little – you are a champion! 💠



Sizzling Fundraiser

In late 2013 CLAN was thrilled to receive a \$300.00 donation from passionate young people who care about our neighbours' children!

In the final term of 2013, four Danebank students organised and carried out a Sausage Sizzle day at school in order to raise money for CLAN. Isabella Cole, Ingrid Stutsel, Marie Tsipidis and April Cussen raised the funds as part of a commerce project that aimed to demonstrate how to run a business.

It is fantastic that the students' project was so successful and all their hard work and organisational skills were rewarded so handsomely. It was very generous of the girls to choose to donate the proceeds of the event to others less fortunate than themselves. The girls strongly support CLAN's goal, and took the opportunity to assist the organisation in any way they could. This is obviously a reflection of the values of the school they attend as well as their own empathy for others. Thank you girls and thank-you Danebank! •



CLAN
Commits2Deliver
to Every Woman
Every Child in 2014

In 2014 CLAN was proud to again commit to the United Nations Secretary General's EveryWomanEveryChild (EWEC) movement, with a focus on continued advocacy efforts and action on behalf of children and adolescents in the context of the unacceptably high burden of preventable disability and death caused by chronic



health conditions and Non-Communicable Diseases (NCDs).

To this end, CLAN committed to action at both the grassroots and global level. At a grassroots level, in 2014 CLAN committed to collaborating with a broad range of partners to help launch a support group for children and adolescents who are living with Rheumatic Heart Disease in Kenya.



At a global level, CLAN committed to striving in its role as inaugural Secretariat of NCD Child to ensure the success of the second international NCD Child Conference, to be held in the Republic of Trinidad and Tobago in March 2014.

CLAN is proud to have successfully delivered on our commitments to EWEC in 2014 and look forward to future efforts to support this important global movement.

CLAN welcomes individual donors and corporate partners. If you would like to support CLAN's grassroots community work, please contact us at info@clanchildhealth.org for more information



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