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# **CONTENTS**

President's Report	1
CLAN Office Bearers	2
About CLAN	3
CLAN's Governance Framework	4
CLAN's Strategic Framework for Action	5
CLAN's Key Achievements	6
CLAN Financials	14
Thank You to CLAN's Special Partners and Friends	22





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.



# PRESIDENT'S REPORT



Dr Kate Armstrong President and Founder of CLAN

## The Power of One Some Sum

Looking back over another year of CLAN's life, it is humbling to reflect on the many partnerships this relatively small Australian Non-Government Organisation (NGO) is so privileged to enjoy. Having started in 2004 and officially launching as an Association with the NSW Department of Fair Trade in 2007, there have been incredible achievements across a range of countries, chronic health conditions and projects in a fairly short space of time.

So much so in fact, that if we are honest, at times it prompts the question... how is this all possible?

It is moments like this that the concept of 'The Power of One' comes to mind, and particular people stand out as truly exceptional. There are many such individuals CLAN has the honour of working with, and I can't possibly mention everyone here, but I will proudly single out the recipient of CLAN's Honourary Membership Award in 2013, Assoc Prof Maria Craig. As a paediatric endocrinologist from Children's Hospital Westmead, Australia, Maria has walked and worked with CLAN on a voluntary basis since 2007, tirelessly giving of herself to health professionals and our Diabetes and Congenital Adrenal Hyperplasia (CAH) community members in Vietnam, travelling at her own expense to attend Club meetings, train health professionals and participate in a very real way to the rise and rise of paediatric endocrinology in Vietnam.

And yet, as we all know, one single person can't be expected to change the world. In fact, CLAN's work with the Diabetes, Congenital Adrenal Hyperplasia (CAH), Nephrotic Syndrome (NS), Autism, Duchenne Muscular Dystrophy (DMD), Osteogenesis Imperfecta (OI) and other communities we partner with around the world has shown us very clearly that it is only when a range of partners come together in genuine and generous collaboration that we see change. It takes not just 'one', but 'some' of us to overcome the gross inequities facing communities of children and families living with these chronic health conditions (also known as Non-Communicable Diseases – NCDs) in low- and middle-income countries.

Indeed, if we step back and look at the issue at a global level, it's clear we need to do even more. CLAN is proud to be associated with the amazing work of NCD Child, because we recognise we don't just need 'some' of us working together for change – we need the 'sum' of us working together for change. We understand the need to shift beyond the health sector, beyond welfare, beyond rhetoric. Collectively we must ALL decide that we will no longer tolerate the inequitable and needless suffering experienced by the many millions of children and adolescents who are living with and at risk of chronic health conditions in resource poor countries. We must ALL consider our own role and become part of the solution. Because the equation for success requires the SUM of us to protect and fulfill the rights of ALL children to the happiest and healthiest lives possible... not just some of the children who are lucky enough to live in wealthier countries.

Sincere thanks to everyone who has joined the journey so far. In our 2012-13 Annual Report, CLAN is proud to reflect on our five strategic pillars for action and share the key achievements made possible through collaborative efforts with our wonderful network of partners and friends. And for those interested in joining this movement for change, please consider what YOU can do to help... The children and families need you... We all do.

Yours sincerely

#### **Kate Armstrong**





# **CLAN OFFICE BEARERS**



Vice President
Cath Cole



Treasurer

Heidi Armstrong



Secretary Boonseng Leelarthaepin



Public Officer Valerie Foley

CLAN Honorary Associate Member – Assoc Prof Maria Craia



In this reporting year, CLAN is very proud and honoured to present Honorary Associate membership to Assoc Prof Maria Craig. Dr Craig is an extremely experienced health professional in paediatrics and child health and in the specialist field of Endocrinology and Diabetes. Dr Craig has been recognised for her experience winning the Australian Paediatric Endocrine Group Young Investigator's Award in 1997 and the Asia Pacific Paediatric Endocrine Society Clinical Teaching Award in 2008. She has been published over 120 times in her career and achieved much as a result of her research in the areas of Diabetes and Epidemiology.

Dr Craig is the current Chair of the APEG (Asia Pacific Endocrine Group) Diabetes Database Committee and Editor for the International Society for Paediatric and Adolescent Diabetes guidelines and her expertise has helped develop paediatric endocrinology as a medical specialty in Vietnam. In addition, her commitment to the Congenital Adrenal Hyperplasia (CAH) and Diabetes Communities of Vietnam since 2007 has been unparalleled, and contributed enormously to their growth and development.

Dr Craig's volunteer commitment to CLAN's work in Vietnam since 2007 has been extensive and certainly has helped strengthen the CAH and Diabetes Support Group Clubs in Hanoi and Ho Chi Minh City which are the visual hub of CLAN's activities under our Strategic Framework

for Action. Many hundreds of families have benefited directly from Maria's wonderful teaching and support over many years, and CLAN sincerely thanks Maria for her overwhelmingly generosity to so many over so many years. 🛟



Committee Member Profile: Sandy Harwood, Office Volunteer Much thanks and appreciation to one of CLAN's newest volunteers, Sandy Harwood, who has taken on the role of CLAN Headquarters Office Volunteer. Sandy Harwood comes to CLAN with a generous heart and a lifetime of nursing experience, and importantly, great organisational skills which has resulted in the development of the CLAN Library. Our library resources are available to any interested person or group and contains abstracts, presentations, books, pamphlets, annual reports and other published articles, multimedia items and all of our translated materials.

Many thanks also to Boonseng Leelethaepin, CLAN's Secretary for ensuring that ISBN numbers are allocated to our published articles and copies distributed in accordance with government requirements. �

# **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 Cift Deduction Scheme (OAGDS) status and endorsed by the Australian Taxation Office as a Deductible Cift 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. �

What is CLAN Doing to Help Children with Special Health Needs?

CLAN identifies a group of children with the same chronic health condition as a distinct community, then supports development through multi-sectoral partnerships at local, national and international levels to drive community priorities.

CLAN's strategic framework for action rests on five pillars:

- 1. Affordable access to medicine and equipment
- 2. Education (of children, families, health professionals, policy makers, national and international communities), research and advocacy
- 3. Optimisation of medical management (holistic care; primary, secondary and tertiary prevention)
- 4. Encouragement of family support groups
- 5. Reducing poverty and promoting financial independence.

At all times the community of children remains the central focus. This ensures the childrens' voices are heard and enables a range of diverse and multi-sectoral stakeholders to unify around a common goal.

CLAN's community development approach ensures local ownership and genuine involvement in evaluation and planning. It has proven sustainable, effective and worthwhile in helping the world's poorest and most vulnerable children and families.

## 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 Cobduct 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 Inc

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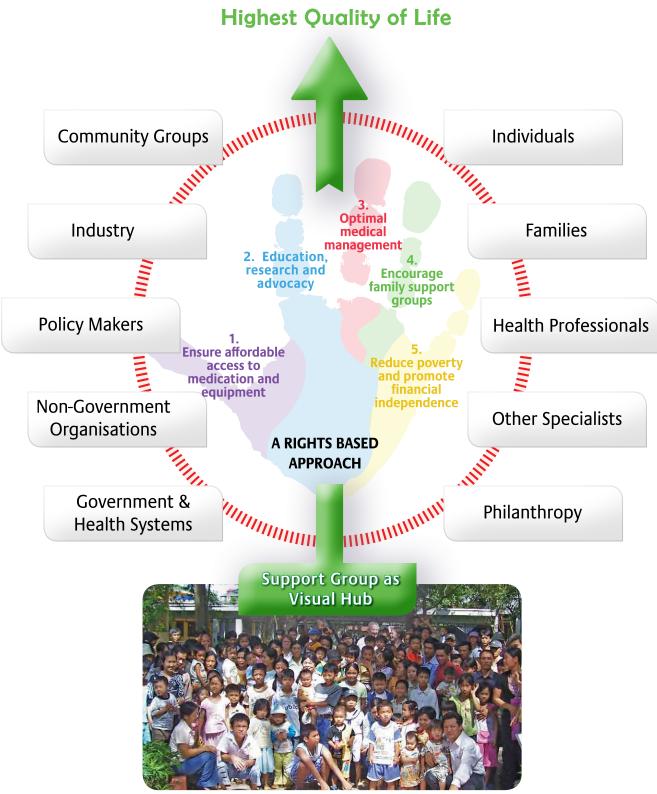
@clanchildhealth



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.

## 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.

Appropriate
Drugs now Legally
Availabile for
Children Living
with Osteogenesis
Imperfecta (OI) in
Vietnam

Report by Professor Craig Munns, Paediatric Endocrinologist, The Children's Hospital, Westmead, NSW, Australia Osteogenesis Imperfecta (OI) is a genetic bone condition 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. Physical disability can significantly limit educational and job opportunities and places a major financial burden on families and the community as a whole.



The single greatest advance in the management of OI has been the use of intravenous bisphosphonates. These are a group of medications that decrease the action of bone resorbing cells (osteoclasts). This allows for the bones to get thicker and thereby stronger. In OI bisphosphonates have been shown to decrease fracture rate, bone deformity and bone pain. This leads to improved spinal deformity, mobility, growth, quality of life and longevity (1). Access to intravenous bisphosphonates is essential for children with OI.

Since the first OI Club meeting that CLAN supported in Hanoi in November 2011, access to the intravenous bisphosphonate, Zoledronate, has increased dramatically, with many children with OI starting treatment. Recent changes to legislation in Vietnam mean that doctors are now able to legally prescribe Zoledronate treatment, and treatment protocols have been established. This life changing medication will increasingly be available to all families and more still needs to be done so that our neighbours' children throughout Asia enjoy the highest quality of life possible.

1. Alcausin MB, Briody J, Pacey V, Ault J, McQuade M, Bridge C, Engelbert RH, Sillence DO, Munns CF. Intravenous Pamidronate Treatment in Children with Moderate-to-Severe Osteogenesis Imperfecta Started under Three Years of Age. Horm Res Paediatr. 2013;79(6):333-40.

Access to
Hydrocortisone
tablets for the
International CAH
Community

Since our founding days in 2004 CLAN has had the privilege of partnering with Alphapharm Pty Ltd (a Mylan Company) to focus on optimising affordable access to hydrocortisone tablets for the CAH communities of the Asia Pacific region that we partner with. An initial partnership in Vietnam was continued until such time as longer-term, sustainable local solutions were identified, and humanitarian donations were able to cease.

CLAN is extremely grateful to Alphapharm for again partnering with CLAN in recent years to

support the Indonesian, Filipino and Pakistani CAH communities, so that children might survive and thrive whilst local supply chains are developed. The lives of well over 1,000 children who are living with CAH in our region have now been saved by Alphapharm's long-term partnership and support.

Thank you Alphapharm! 💠





## 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.

Meeting Educational Requirments of Families with CAH in Vietnam and Indonesia

A report by Irene Mitchelhill, Clinical Nurse Consultant, Sydney Children's Hospital, Randwick, NSW Australia



In 2012 CLAN was able to meet the educational requirements of families with CAH in both Vietnam and Indonesia, by providing an educational resource in DVD format. Health education is an integral part of the health professional role, and critical to the needs of families with chronic conditions.

With the increased incidence of CAH in Vietnam and the remote location of many families in rural areas, improving access to educational resources was considered a priority. In November 2011, a translated version of an educational resource developed for families with CAH in Australia in DVD format, was launched to health professionals at the Asia Pacific Paediatric Endocrine Society (APPES) Continuing Medical Education (CME) meeting in Hanoi, Vietnam. This comprehensive educational program titled 'Psychosocial Education Program (PEP) for Families with CAH' was launched to families at the CLAN CAH Club meetings in Hanoi in July 2012 and in Jakata, Indonesia, in November 2012. Included with the PEP, is the CAH knowledge assessment questionnaire (CAH KAQ), which provides a means of evaluation of patient/family knowledge and the PEP. Each family attending the Club meetings, were provided with a copy of the DVD for their personal use, with duplication of the DVD gratefully sponsored by CLAN. In addition, medical professionals have been able to also use the DVD for medical and nursing training of their staff.

The opportunity to translate this educational resource into other languages came about through the volunteer efforts of four doctors, working in Vietnam and Indonesia, who undertook the task of translating the verbal transcriptions and PowerPoint slides for the DVD. A health service interpreter then narrated the transcript, with completion of the DVD, edited by a media production company, in line with the original filmed speaker presentations.

The program includes the following five chapters: What is CAH, Adolescent and Adult Issues, Psychological Issues, Sick Day Management, and Emergency Injection of Hydrocortisone. Each presentation has been carefully developed to address the essential information, which is required to understand and manage CAH.

This innovative move to provide education using multimedia methods has the ability to revolutionise the educational process. It is cost effective, can be revised by individuals as required, and may be updated when needed. Such learning methods, which are patient specific, structured and culturally sensitive are appealing to all, but particularly to those with both literacy and language issues. Audio and video formats (CD or DVD) which provide descriptive diagrams, illustrations and demonstrations, appeal to all learning situations, but should also be combined with written information to provide a comprehensive approach.

I would like to sincerely thank CLAN for the opportunity to be involved in such a fantastic project, their sponsorship of the DVD production and duplication, and for being able to share my expertise in providing education and support for the families and health professionals of

Vietnam and Indonesia. The experiences have been amazing and humbling and set me on a journey that I was looking for.  $\diamondsuit$ 

Panel discussion with families and health professionals at the November 2012 CAH club meeting in Jakarta.



Research Helps us Learn from our Grassroots Communities CLAN's community development approach means that consultation with the families we work with and learning from them the best ways to effect sustainable change for the children is a vital part of our work. A formal research project that initially focused on Nephrotic Syndrome in Vietnam

has now facilitated broader Health Needs Assessments in partnership with the Ol and DMD Communities in that country as well.

CLAN is proud to co-author with our colleagues on projects research the results of our health needs assessments. At the 7th Asia Pacific Paediatric Endocrine Society (APPES) Biennial Scientific Meeting in Bali, November 2012, colleagues from Vietnam presented results on the analysis of data collected at the OI Club meeting at the National Hospital of Pediatrics, Hanoi in November 2011, as well as evaluation findings from CAH and Diabetes Club meetings at Children's Hospital 2. Ho Chi **Publications** Minh City. and presentations international conferences on information shared by families will continue to



support capacity building and provide focus for future collaborative action.

Children, Adolescents and NCDs – A Community Development Approach to Acheiving Rights in Health

Report by Laura Healy



## **ACFID Child Rights Working Group Conference**

In March this year, I was fortunate enough to have the opportunity to represent CLAN at the ACFID Child Rights Working Group Peak Event, 'Reframing the youth bulge – from problem to solution'.

This one day conference sought to explore the potential the increasing population of young people presents in realising development goals and increasing innovation within the sector. Through a combination of plenary sessions, presentations and workshops, the conference provided a platform upon which issues impacting youth within the context of international development could be discussed and possible solutions could be explored.

On behalf of CLAN I presented within the Health and Development session and sought to outline CLAN's community development approach to achieving the rights to health. I had the chance to engage with a range of professionals from the international development sector and share CLAN's strategic framework for action to redress the global inequities facing children and adolescents living with NCDs in low and middle income countries. I sought to emphasise how through providing meaningful opportunities for young people to engage in and influence efforts to promote the rights to health of their peers, CLAN is achieving population based sustainable change.

The conference provided an important opportunity to highlight the significant burden NCDs place on social and economic progress and the need to tackle this growing global epidemic.



## 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.

Children and Adolescents on the Global Non Communicable Disease Agenda Starting in 2011 as a project managed by CLAN, NCD Child has now developed into an independent global coalition that supports, engages in, and advocates for discussion, policies and programs that encompass:

- Considerations of child-specific issues of NCD related premature mortality, morbidity, and disability
- A life-course focus and rights based approach
- Actions on the social determinants of health
- Empowering the community and engaging with young people to be agents of change, especially giving them a voice in the global arena
- Creating a knowledge sharing platform for the exchange of ideas and collaborative projects
- Engaging multi-sectoral partners, fostering partnerships and strengthening communication channels.

Following an inaugural NCD Child Conference in March 2012 (see CLAN 2011-2012 Annual Report), NCD Child has continued to establish itself as an independent organisation through the use of social media and broader participation in the global health and development discourse.

CLAN's Role as Secretariat of Global Coalition NCD Child

Caring & Living As Neighbours

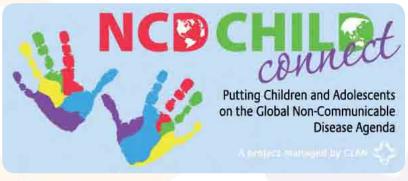
The NCD Child Secretariat was initially established as a global coalition of founding members, with the Secretariat designed to be a rotating entity, voted on annually by an Advisory Council. CLAN was elected to commence work as the inaugural Secretariat of NCD Child in early 2013, and Dr Kate Armstrong (President of CLAN) was elected the inaugural Executive Secretary of NCD Child.

In 2013, the NCD Child Secretariat oversaw the day-to-day operational aspects of NCD Child, in line with the agreed vision, mission, goals and objectives of the coalition and was responsible for the successful delivery of agreed deliverables in consultation with the Advisory Council and membership.

The core objectives of NCD Child are Advocacy, Building Community Capacity and Collaboration.

Key accomplishments of NCD Child in 2012-13 included:

- Strategic organisational development and launch of NCD Child as a global coalition
- Participation at key international events such as the 66th World Health Assembly and ECOSOC
- Development of key publications and advocacy tools, such as papers linking NCDs, young people and a need for decent work, and a submission to the Commonwealth Secretariat Health Minister's Meeting, May 2013 around children, adolescents and mental health
- Continued development of our communication strategy and focus on partnership with UNICEF to support the inclusion of NCDs within their flagship publication Facts For Life



- Regular submissions to the World Health Organisation's Global Action Plan and Global Monitoring Framework for the Prevention and Control of NCDs, as well as the UN Global Thematic Consultation on Health in the Post 2015 Agenda
- Integrating maintenance and development of NCD Child's website and social media accounts
- Circulation of communications in particular launch of the e-newsletter NCD Child Connect.

## ECOSOC July 2012

NCD Child was proud to collaborate with UNICEF and The Pan American Health Organization (PAHO) around a side event at The United Nations Economic and Social Council (ECOSOC) in July 2012. NCD Child published an Issues Paper titled 'Working Well - Safe-quarding Adolescent and Youth Livelihood in the Face of NCDs and their Risk Factors' (pictured) to launch at the ECOSOC event, and were thrilled that NCDs were included within the 2012 ECOSOC Declaration for the first time, largely as a result of these advocacy efforts.



Sixty Sixth World Health Assembly, May 2013

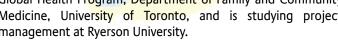
NCD Child continued to advocate for children and adolescents within global NCD, health and development discourse at the World Health Assembly (WHA) in Genenva, May 2013. NCD Child thrilled was when Member States acknowledged the fact "Children can die from treatable noncommunicable diseases, such as rheumatic heart disease, type 1 diabetes, asthma, and leukaemia, if health promotion, disease prevention, and comprehensive care are not provided" (Omnibus Resolution on NCDs approved by Member States, page 8, para 2.) 🛟



**Project Manager** Profile: Rose Rodas Rose Rodas joined NCD Child in early 2013 as Program Manager. She has a BSc from York University and an MPH from the Chinese University of Hong Kong.

During a research fellowship at the School of Public Health and Primary Care at the Chinese University of Hong Kong in the Asia-Pacific region, her interest for post-disaster NCD management arose and she has been interested in NCD work since then.

Rose also holds a position as program coordinator for the Global Health Program, Department of Family and Community Medicine, University of Toronto, and is studying project management at Ryerson University.





Rose speaks English and Spanish. <

Founding Members of NCD Child

The NCD Child Advisory Council Founding members include: AAP/IPA (American Academy of Pediatrics / International Pediatric Association); AYUDA (American Youth Understanding Diabetes Abroad); CLAN (Caring & Living as Neighbours); Global Taskforce for Cancer Care and Control (GTF.CCC) / Harvard Global Equity Initiative (HGEI); Johns Hopkins University; Medtronic (Incorporated & Foundation); PHI (Public Health Institute); Save The Children; The Geddes Group; and UNICEF. <























## 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.

Improved Health
Outcomes for
Children living with
Nephrotic Syndrome
in Vietnam

CLAN was proud to again partner with health professionals and families in Vietnam to successfully hold Nephrotic Syndrome (NS) Clubs at all three children's hospitals in the country. Over 400 families attended, and the Club meetings were a great opportunity for community members to reconnect and learn more about the best ways to help their children enjoy the highest quality of life with NS.

Since NS Clubs were first started in Vietnam in 2011, much has changed, with medications now available on the national insurance scheme; more children with NS attending school;

and admission rates to hospital dropping markedly now that parents are more informed and active participants in the provision of their children's healthcare.

The February 2013 meetings focused on reporting back to the NS Community the results of previous health needs assessment surveys. Not only did families enjoy hearing what had been learned about NS in Vietnam, but myths and misunderstandings held by large numbers of parents were able to be addressed in targeted education sessions.

Sincere thanks to Dr Elisabeth Hodson for her tireless support of the NS Clubs in Vietnam; to Dr Yen-Thanh Mac for her incredible work as CLAN's Program Manager in Vietnam; and also to NephCure for giving CLAN permission to translate into Vietnamese language an inspirational video sharing encouraging messages from a child who is living with NS in America.



The Power of Words and Dance

For children and families who are living with Nephrotic Syndrome (NS) in Vietnam, without doubt one of their greatest fears is that the condition will progress to kidney failure. Although this is a relatively rare occurrence (the vast majority of children with NS go on to perfectly healthy adult lives if managed well as children), it is sadly a reality for some. At the February 2013 NS Club meeting, families received an informational newsletter, with key tips on the best

ways to care for their children at home, and reduce the risk of future complications from NS.

Families were also thrilled to watch a beautiful dance performance by a talented, gorgeous young woman who had a kidney transplant successfully completed at the National Hospital of Pediatrics in Hanoi in 2012, and is now living a happy, healthy and active life free from dialysis machines. Inspirational for everyone who attended!



Strengthening Existing Health Systems **CLAN** understands that it is far better to focus on activities and projects that strengthen existina health systems and communities than to create parallel systems. To this end, running educational sessions for health paediatric professionals at major hospitals, with a specific focus on inviting health professionals from rural areas to attend, is proving a sustainable and cost effective model.

Our sincerest thanks to the many experts from Australia and beyond who have travelled to work with our community networks – your time and generosity of spirit truly mean the world to us.



Ann Robinson, Dr Sue Ditchfield, Mr Doan Nguyen Xuan and Helena Young at the DMD club meeting, Hanoi, Vietnam.



Professior Craig Munns lecturing health professionals in Hanoi, Vietnam on Ol.



Dr Elisabeth Hodson shares updates on NS at Children's Hospital 2 in HCMC, Vietnam.



Helena Young, Dr Kristi Jones, Dr Sue Ditchfield, Dr Vu Chi Dung and the team from C3, Vietnam celebrate the DMD club meeting.

CLAN's Great Rainforest Ramble to Raise Funds for DMD and OI Clubs







From 10 to 12 August 2012 at Mt Keira Scout Camp, Mt Keira near Wollongong, NSW our dedicated walkers gathered together again to raise funds to help children living with Duchenne Muscular Dystrophy and Osteogenesis Imperfecta in Vietnam. CLAN's Rainforest Ramble involved 35 walkers traversing 25 kilometeres of the Illawarra escarpment under the glorious canopy of the natural rainforest. It was a very cold and wintery trek completed over two days, but this was compensated for with pots of hot food and great entertainment. A range of bands entertained over 90 guests who flocked in for the Saturday night. Bands included the locally based Con Artists from the Conservatorium of Music, My Secret Window, The Hancock Brothers and Mark Wallis.

With this event and the 'Big Night Out' held in May, CLAN raised funds in excess of \$10,000 to strengthen and support the DMD and OI Communities of Vietnam by helping to establish Support Group Clubs for these two conditions. CLAN is also extremely grateful to our wonderful sponsors at State Custodians Mortgage Company for getting behind our big night out.

Many thanks to Steve McClure for his genius in organising, Trish McClure, Mandy and Daryl Herbert, Chris and Helen Richards, Kate and Dave Hansen, Bob and Caz Armstrong, Mark Wallis and Robyn Kindt for all their hard work. A special thanks also to Peter Cole and our other special helpers in the kitchen. Final thanks also to the team at Cardno for their generous sponsorship of our walking shirts and helping us raise much needed funds for the DMD and OI communities of Vietnam.

This event and those of the past two years – CLAN walks Jervis Bay (2011) and CLAN walks the Six Foot Track (2010) – could never have happened without the help of these very generous people. These events are super special because of the music – it naturally brings us together. Lastly, thanks to our walkers, especially those who have made it three years in a row!!! You are all amazing!

## **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!

The OI Community of Vietnam Grows Stronger!



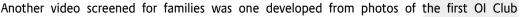


The second ever Osteogenesis Imperfecta (OI) Club (Support Group) meeting in Vietnam was held on 9 May at the National Hospital of Pediatrics (NHP) and around 75 families attended. The OI Club meeting was scheduled for a date near 6 May deliberately, to help families connect with the international Wishbone Day movement, a day of awareness held on 6 May every year.

Families and their children attended from all over Vietnam to learn about the management of OI and how they can best help their children.

The day commenced with the screening of a music video produced by CLAN to encourage and inspire the OI Community. The song, No. Dreams Too Big, was beautifully performed by Ms Nguyen Phuong Anh, a young woman who is living a full and active life with OI in Vietnam. It was written by Mrs Jessamine





meeting which was held in November 2011 and the many children in the audience delighted in seeing themselves on the screen. CLAN is very fortunate to have the support of media company C3Vietnam who produced these videos and also filmed the recent meeting.

Dr Craig Munns and Helena Young presented at the meeting and this was followed by a lively Q and A session.

Families at the OI Club meeting enjoyed socialising over lunch. Later in the day the OI Club executive members were elected and there was an opportunity for discussion of the issues faced by families. CLAN is grateful to local health professionals and the Ministry of Health in Vietnam for working so hard to ensure that the life changing medications, bisphosphonates, are available to children with OI in Vietnam. The media also attended the meeting giving much needed publicity to the lack of availability of medication for these children.

Huge thanks to everyone who made this day possible - especially the many families who travelled such long distances to attend. CLAN would also like to acknowledge the contribution of several Australians who travelled to Vietnam to support this meeting. In particular, Assoc Prof Craig Munns, Dr Kristi Jones and occupational therapist, Helena Young, all from The Children's Hospital at Westmead, Sydney, Australia and Mrs Ann Robinson, an endocrine nurse practitioner from Queensland. The support of these volunteers was invaluable, and CLAN could not do the work we do without your help! �





## DMD Club Report – May 2013

www.duchennevietnam.com clbdmdvietnam@gmail.com On 10 May 2013 the very first meeting of the Duchenne Muscular Dystrophy (DMD) Club of Vietnam was held at the National Hospital of Pediatrics in Hanoi. Over 100 families attended.

With thanks to funding from MDNSW (Muscular Dystrophy NSW), CLAN was proud to present all families with a new educational resource on DMD in Vietnamese language. This was a fantastic step forward for DMD management in Vietnam. Special thanks must also go to Paediatric Geneticist and DMD Specialist Dr Kristi Jones and Occupational Therapist, Helena Young – both from The Children's Hospital at Westmead for volunteering their time



Mr Doan Nguyen Xuan (pink shirt) and Dr Sue Ditchfield talking after the MD Club meeting.

Hospital at Westmead for volunteering their time and energy.

Two amazing young people Doan (Mr) and Van (Ms), who are both living fulfilling lives with MD, spoke of their experiences and inspired everyone who attended. They emphasised the importance of attending school and engaging in all life has to offer. These young people both have careers and were later elected President and Vice President of the newly formed DMD

Club of Vietnam. Doan has since set up a web site that includes a discussion forum for the group.

By the end of the day, all members of the new DMD Community of Vietnam had many of the resources and connections they need to move forward in a strong and empowered way.

CLAN would like to acknowledge the contribution of Dr Yen-Thanh Mac, the CLAN Vietnam Project Manager who oversaw CLAN's involvement in support of this important event.



CAH Support Group Meeting in Jakarta

Report by
Dr Sue Ditchfield

The Congenital Adrenal Hyperplasia (CAH) Support Group meeting was held on 18 November 2012 in Jakarta.

CLAN is very grateful for the assistance of Dr Aman Pulungan, Mrs Borneica Sharry and Dr Frida Soesanti who made it possible for CLAN members from Australia to attend. We were also very fortunate to have Dr Jamal Raza, Director of the National Institute of Child Health (NICH) in Karachi along to share his experiences of managing CAH in Pakistan.

The day began with a press conference where the difficulties of accessing hydrocortisone and fludrocortisone in Indonesia were shared with the media. A hands-on injection session was run by Irene Mitchelhill from Sydney Children's Hospital. A DVD on CAH, written by Irene and translated into Indonesian by Dr Angie Dijksak and Dr Amy Prawira, was provided to each family. Dr Dijksak was also able to attend the meeting and video the proceedings. The day was very informative and a great experience for all involved. We look forward to growing CLAN in Indonesia and strengthening ties with all involved in the CAH community.



Left: Some of the children in attendance at the CAH Support Group.

Right: Dr Jamal Raza (NICH), Ms Irene Mitchelhill, Borneica Sharry, Chris Healy, Dr Sue Ditchfield, Mr Sharry and two of the Sharry children.

## 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.

CLAN Starts
Work on Helping
Financially
Disadvantaged
Families

Report by Jim Willett

In 2012-2013, CLAN started work on a project to address the needs of families who were struggling to meet the additional living costs caused by the chronic health conditions of their child or children. This is one of the five pillars of CLAN's Framework for Action, 'Reduce Poverty and Promote Financial Independence'. It is estimated that nearly half of the 650 families in the Hanoi who have children with CAH are financially disadvantaged.

The project commenced work in July 2012 at the Hanoi CAH Club meeting where the Chairman of the Club, Mr Tran Trung Kien introduced the Australian Business Volunteer, Jim Willett to the families and explained the background to the project. On the advice of Mr Kein and Dr Dung from the National Hospital of Paediatrics it was decided to concentrate on families from rural areas, as this was where families were experiencing the greatest financial hardships.

Jim Willett, in many cases accompanied by Mr Kien, visited twenty two families in their homes where an understanding of their current financial situation and their plans for the future were discussed. Based on this information a technique was developed to identify the families that were in greatest need of assistance. Based on an analysis of their monthly incomes and their forward plans to improve their financial position, around 35% or about 120 families were identified as being in urgent need of assistance. In general terms, the task identified was to lift the average income from \$A200 to \$A400 per month. At a monthly income level of \$A400 most families could provide for their families, including meeting their costs of education. There are exceptions, where for example more than one child in a family was suffering from a chronic health problem.

The project recommended that a Program Manager be appointed to work with groups of families on first improving their existing commercial or income generating activities and then to assist with identifying new initiatives to further help those families.

The form of this assistance would vary depending on the nature of the family's project and the

ability of the family to implement the new initiative. In some cases a small loan would be sufficient to assist a family to implement their plan while in other cases a loan guarantee or advice and training for example would be necessary.

There was a wide range of possible projects discussed with families, which indicated that with some support many families could be assisted and thus their financial situation improved. This provided further evidence that Pillar Five of CLAN's Framework for Action was relevant and an important consideration for all of these families.

Jim Willett would like to thank CLAN, Mr Kien and all the families for the opportunity to work on such a rewarding project. The families were very open and shared many personal details, which gave him a rich insight into the lives of a remarkable group of people. Jim hopes that he will be able to be part of the implementation of this project in the future.

# **CLAN FINANCIALS**

## Committee's Report for the Year Ended 30 June 2013

Your committee members submit the financial accounts of the CLAN (Caring And Living As Neighbours) Incorporated for the financial year ended 30 June 2013.

Kelly Leight

#### **Committee Members**

Dr Kate Armstrong Robert Armstrong

Heidi Armstrong Dr Sue Ditchfield Dr Yen-Thanh Mac

Catherine Cole Amy Eussen Peter Watt

Valerie Foley Laura Healy Dr Andrea Zalan

Dr Boonseng Leelarthaepin Michelle J Konheiser

## **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 2013 Year ended Prev Year End

\$89,505 \$6,409

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

**Dr Kate Armstrong** Committee Member

Catherine Cole
Committee Member

## Independent Auditor's Report to the Members for the Year Ended 30 June 2013

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

The accompanying notes form part of these financial statements.

# Income and Expenditure Statements for the Year Ended 30 June 2013

	2013	2012	» Public	-	-
	(\$)	(\$)	» Gov't, multinational & private	e -	-
INCOME			» Accountability & Administrat	ion -	
DONATIONS & GIFTS		-	› Accountancy	2,549	1,340
» Corporate donations	1,300	1,449	Advertising & promotion	1,440	-
» Personal donations	29,292	8,075	ACFID fees	1,568	1,702
» Non-monetary	-	-	› Bank charges	509	267
BEQUESTS & LEGACIES			Conference fees	-	1,822
» Grants	_	-	› Depreciation	439	1,318
» AusAID	_	-	General expenses	-	375
OTHER AUSTRALIAN	_	-	) Indonesia training	1,331	-
» APPES grant	3,000	0	) Insurance	2,613	2,548
OTHER OVERSEAS	2,223	· ·	NCD Child conference	6,186	51,022
» Medtronics grant	182,677	-	› Printing & stationery	6,926	8,056
INVESTMENT INCOME	,		› Subscriptions	2,340	-
» Westpac interest	1,628	1,104	) TeleConferences	1,419	1,336
OTHER INCOME	-	80	Travel, accom & conference	8,229	-
» Members subscriptions	500	411	Translation & printing	8,978	11,423
» NCD Child projects	-	70,139	› Web design	5,782	2,236
» Steve Jones FunRaising	-	4,100	» Non-monetary expenditure	-	-
» Walk FundRaiser	8,711	33,517	Total International Aid & Deve Expenditure	lopment Prog 137,603	rams 112,386
» Revenue for international expediture	political or religio	ous adherence -	INTERNATIONAL POLITICAL OR EXPEDITURE	RELIGIOUS AE	OHERENCE
» Adherence Promotion pro	ogram -	-	» Programs expenditure	-	-
Total Income	227,108	118,795	» Domestic programs expendit	ture -	-
EXPENSES			. •	137,603	112,386
INTERNATIONAL AID & DEVE EXPEDITURE	ELOPMENT PROGR	AMS	Profit from ordinary activitie before income tax	es 89,505	6,409
» International Programs			Income tax revenue relating to	)	
Consultants' fees	54,836	2,586	ordinary activities	-	-
Overseas medication	73	2,586	Net profit attributable to the association	e 89,505	6,409
Overseas training	1,815	5,124	Total changes in equity of th		0,403
Overseas hospitals	27,416	14,343	association	89,505	6,409
Overseas travel/accomm		6,623	Opening retained profits	45,258	38,849
» Funds to international pro		, -	Net profit attributable to the	00.505	
» Programs support costs		-	association	89,505	6,409
» Community education	-	-	Closing retained profits	134,763	45,258
» Fundraising costs	-	-			
GoFundRaise fees	240	264			
y Goruliakaise tees	240	204			

The accompanying notes form part of these financial statements.

# Income and Expenditure Statements for the Year Ended 30 June 2013

2013		2012 (\$)	(\$)	
CURRENT ASSETS				
Cash and cash equivalents	2	133,030	44,268	
Trade and other receivables		1,514	332	
Inventories		-	-	
Asses held for sale		-	-	
Other financial assets		-	-	
Total Current Assets		134,544	44,600	
NON-CURRENT ASSETS				
Trade and other receivables		-	-	
Other financial assets		-	-	
Property, plant and equipment	3	219	658	
Investment property		-	-	
Intangibles		-	-	
Other non-current assets		-	-	
<b>Total Non-Current Assets</b>		219	658	
CURRENT LIABILITIES				
Trade and other payables		-	-	
Borrowings		-	-	
Current tax liabilities		-	-	
Provisions		-	-	
Other		-	-	
<b>Total Current Liabilities</b>		-	•	
NON-CURRENT LIABILITIES				
Borrowings		-	-	
Other financial liabilities		-	-	
Provisions		-	-	
Other		-	-	
Total Non-Current Liabilities		-	-	
Total Liabilities		-	-	
Net Assets		134,763	45,258	
EQUITY				
Retained profits		45,258	38,849	
Reserves		-	-	
Retained profits		134,763	45,258	
Total Members' Funds		134,763	45,258	

The accompanying notes form part of these financial statements.

## Statement of Cash Flows for the Year Ended 30 June 2013

	2013 (\$)	2012 (\$)	
CASH FLOW FROM OPERATING ACTIVITIES			
Receipts from customers	224,298	-	
Payments to suppliers and employees	(137,164)	-	
Interest received	1,628	-	
Net cash provided by (used in) operating activities (note 2)	<mark>8</mark> 8,762	-	
Net increse (decrease) in cash held	<mark>88,</mark> 762	<u> </u>	
Cash at the beginning of the year	<mark>44,</mark> 268		
Cash at the end of the year (note 1)	133,030	7	
	2013 (\$)	2012 (\$)	

#### NOTE 1 Reconciliation of Cash

For the purposes of the statement of cash flows, cash includes cash on hand and in banks and investments in money market instruments, net of outstanding bank overdrafts.

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

CLAN Inc	-	1,405
CLAN Inc Interest	-	1,020
CLAN Donations	4,534	25,762
CLAN Fund	1,051	6,276
CLAN Fund Interest	127,446	9,804
	133,030	44,268

## NOTE 2 Reconciliation of Net Cash Provided By/Used In Operating Activities to Net Profit

Operating profit (loss) after tax	89,505	-
Depreciation	439	-

Changes in assets and liabilities net of effects of purchases and disposals of controlled entities:

Net cash provided by operating activities	88.762	
Increase (decrease) in sundry provisions	(1,182)	-

No single appeal, grant or other form of fund raising for a designated purpose generated 10% or more of the organisation's international aid and development revenue for the financial year.

## Financial Statements for the Year Ended 30 June 2012

#### 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) 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.

## Financial Statements for the Year Ended 30 June 2012

NOTE 2: Cash Assets	2013	2012
Bank accounts:		
CLAN Inc	-	1,405
CLAN Inc Interest	-	1,020
CLAN Donations	4,534	25,762
CLAN Fund	1,051	6,276
CLAN Fund Interest	127,446	9,804
	133,030	44,268
NOTE 3: Property, F	Plant & Equipment	
NOTE 3. Property, P	-idit & Equipment	
Leased plant and equip	ment:	
At cost	4,463	4,463
Less: Accumulated an	nortisation (4,244)	(3,805)
	219	658
	219	658

## Statement by Members of the Committee for the Year Ended 30 June 2013

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

**Catherine Cole** Vice President

I, Dr Kate Armstrong of 13 Fourth Avenue, Denistone NSW 2114; and I, Catherine Cole of 72 Shoalhaven Road, Sylvania Waters NSW 2224 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 23 November 2011.
- 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.

**Dr Kate Armstrong** Committee Member Catherine Cole
Committee Member

# THANK YOU TO CLAN'S SPECIAL PARTNERS AND FRIENDS

Alphapharm Australia CLAN is grateful to have enjoyed a decade long partnership with Alphapharm, a company that has been researching, developing and making generic medicines



in Australia for more than 30 years and has chosen to share their expertise with those less fortunate than the many millions of Australians who benefit from their generic products annually. Globally, Alphapharm is part of Mylan Inc., which ranks among the leading generic and specialty companies in the world and provides products to customers in more than 140 countries and territories. Alphapharm's values of innovation, integrity, reliability, teamwork and service shine through in their partnership with CLAN.

Medtronic (Incorporated & Foundation) Medtronic is the world's largest medical technology company, offering an unprecedented breadth and depth of innovative therapies to fulfill their mission of alleviating pain, restoring health, and extending life. Since Medtronic was founded, they



have contributed more than \$668 million in Medtronic Foundation grants, Medtronic cash contributions, and medical device donations to improve the health of people and communities. Medtronic's generous support of NCD Child was instrumental to helping CLAN manage its successful launch in 2013.

International NCD
Communities

CLAN would like to express our special thanks to Jessamine Rhae, friend of the Filipino Osteogenesis Imperfecta (OI) Community, who generously shared her beautiful song on OI titled 'No Dreams Too Big' with CLAN to inspire and encourage the Vietnamese OI Community as they celebrated Wishbone Day on 6 May 2013. The song was performed by the talented Nguyen Phuong Anh, and we can't thank the fantastic team at C3 Vietnam enough for the beautiful video they created for us all to enjoy.

Translation of DMD Education Resource



CLAN is extremely grateful to Muscular Dystrophy Association



NSW (MDNSW) for their support of the printing of the DMD Booklet in Vietnamese language. Access to information such as this booklet is an enormous help to all in maximising the quality of life of children living with this condition.

Support of CLAN's Inaugural Program Manager in Vietnam CLAN is extremely grateful to philanthropists Jenni and Andrew McMahon who have generously enabled us to employ a Program Manager in Vietnam for the first time. Dr Yen-Thanh Mac (pictured) has achieved amazing results just in her first term of the role, and there is no doubt our communities are already benefiting enormously from the on-the-ground, local and culturally sensitive support, professional expertise and organisational skills she brings to our work in Vietnam.



Asia Pacific Paediatric Endocrine Society (APPES) The Asia Pacific Paediatric Endocrine Society (APPES) was formed in 1999 to provide a professional forum for those with an interest in Paediatric Endocrinology in the Asia Pacific region. CLAN has enjoyed a long and fruitful partnership with APPES, and is extremely



grateful for the grant we received to continue building the capacity of APPES members in lower-income regions to achieve all they dream of for the children they care for.



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