



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.



ACFID
MEMBER

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Below: The OI (Osteogenesis Imperfecta) Club in Karachi, Pakistan, being entertained by a magician.



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PRESIDENT'S REPORT

**Caring and Living
As Neighbours ... So
we #LeaveNoChild
Behind ...**

It's a big call, but more than a decade on CLAN is still striving to achieve our vision of equity for children living with chronic health conditions in resource poor settings. More than ever, CLAN is committed to the ideal that EVERY child matters and we are witness to the sustainable, scalable change achieved when good people work together for the good of people.

And there perhaps beats the true heart of CLAN ... People.

CLAN's strategic framework for action demands a rights-based, person-centred and community development approach. The five pillars – upon which all of CLAN's work is focused – emerged from detailed consultation with families and young people living with a chronic health condition (Congenital Adrenal Hyperplasia) in a low income country in 2005... Unwilling to accept the gross inequity experienced by children at the time, CLAN invited all families in the country who had children living with the same condition together as a united community, and then asked the families and young people what they believed was needed to achieve the highest quality of life for all children in their community.

Families and youth were very clear – and the five priorities they identified have stood the test of time. Consultation with other communities around the world since then have consistently endorsed the five pillars as a robust starting point for collaborative action aimed at redressing global inequities for children living with non-communicable diseases (NCDs) and other chronic health conditions. When underpinned by a person-centred approach that prioritises engagement of communities of people living with NCDs, we have seen great things are possible.

CLAN is always enormously grateful to the many fantastic people we work with around the globe to drive change for children living with NCDs and other chronic health conditions. We are always saddened when some people leave, and were devastated by the passing of Nguyen Xuan Đoàn, the inaugural President of the Duchenne Muscular Dystrophy Club of Vietnam, in September 2014. CLAN would like to dedicate this year's Annual Report to Đoàn. CLAN also farewelled two of our long-standing committee members in 2015, Drs Sue Ditchfield and Boonseng Leelarthaepin, and we thank them most sincerely for their tremendous efforts and contributions to CLAN's work over the years.

We hope that you enjoy reading about CLAN's activities over the last year. Thank you again to everyone who has given so much, for so long, to so many... Together we are making a difference for our neighbours' children in our efforts to Leave No Child Behind! ✿



*Nguyễn Xuân Đoàn presents a gift to
His Excellency Hugh Borrowman, Hanoi, 2014*

CLAN OFFICE BEARERS



**President and
Founder of CLAN
DR KATE ARMSTRONG**



**Vice President
and Secretary
CATH COLE**



**Treasurer
HEIDI ARMSTRONG**



**Public Officer
VALERIE FOLEY**

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

An Innovator Bringing Communities Together to Drive Change

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

Our model is built around five pillars of action:



1: Access to Medicines and Equipment



2: Education, Research and Advocacy



3: Optimal Medical Management



4: Strong Support Groups



5: Financial Independence

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
- ✿ prioritising a person-centred approach, building creative and trusting relationships with the people in the countries we work creating an inclusive, collaborative, flexible and responsive approach wherever possible
- ✿ 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 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 underpinned by integrity. However, should there be a time when we are not seen to be acting in this way, a complaint can be lodged with the President of CLAN or the CLAN Executive Committee in accordance with our Complaint Management policy.

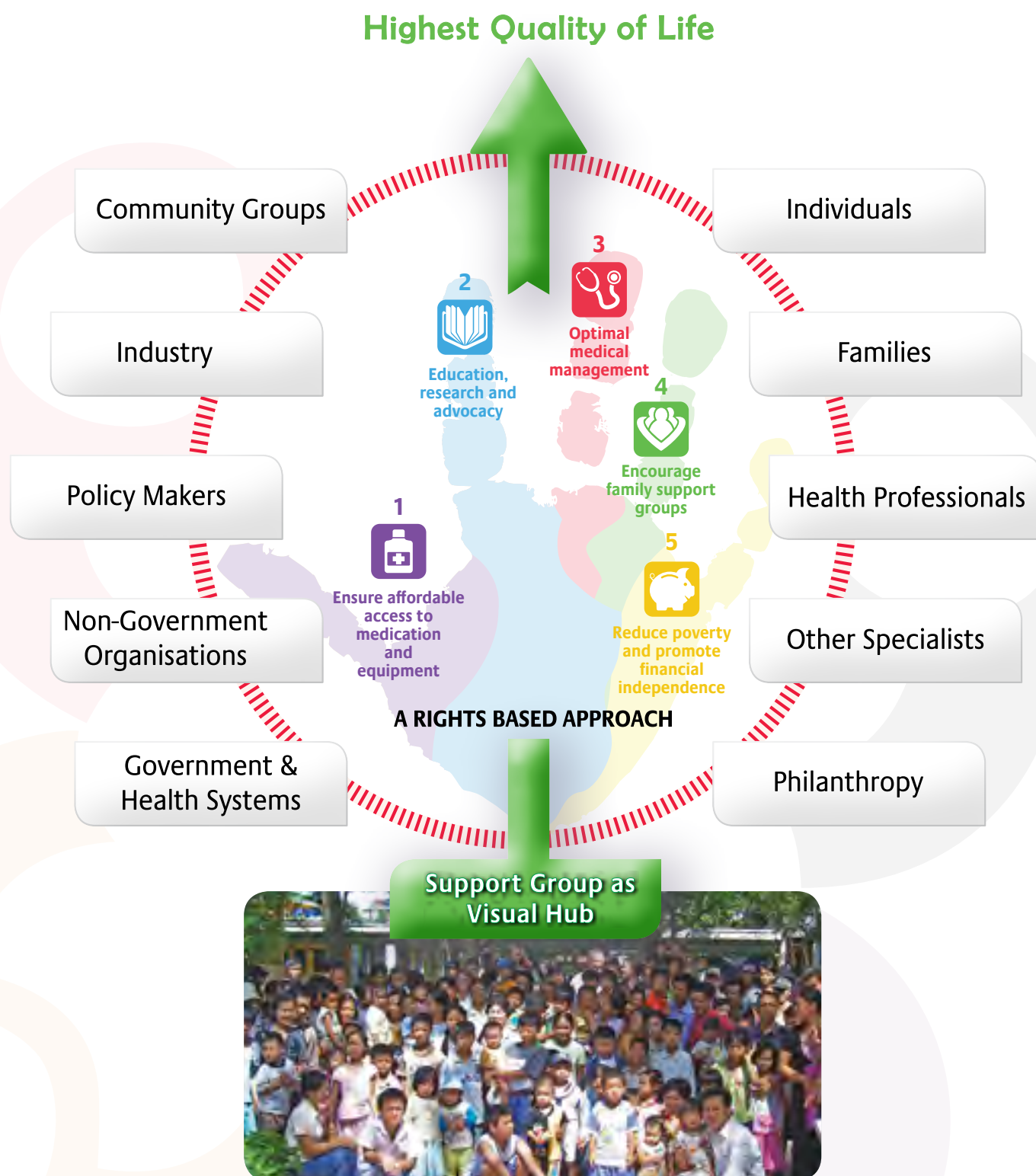


ACFID
MEMBER

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 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 children and families themselves are virtually powerless to effect change without the support of 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 met regularly for support.



PILLAR ONE: Affordable Access to Medication and Equipment

Families of children who are living with chronic health conditions in resource poor settings 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.

CLAN partners with the private sector to drive sustainable change



CLAN is very grateful to our long-term partners at Alphapharm Australia Pty Ltd for their ongoing commitment to children living with Congenital Adrenal Hyperplasia (CAH) in resource-poor countries.

Children with CAH in Australia enjoy affordable access to hydrocortisone and fludrocortisone, two medicines on the World Health Organisation's Essential Medicines List for Children (WHO EMLc). In Pakistan, the CAH Community's experience is very different. Neither drug is locally registered or sold in the country, and families are forced to purchase drugs of dubious quality and very inflated cost on the black market.

With thanks to the generosity of Alphapharm's donation of a short-term, humanitarian supply of Hydrocortisone, doctors in Pakistan are now able to help the children access hydrocortisone tablets whilst they focus their efforts exclusively on seeking local registration of hydrocortisone tablets and a long-term, sustainable solution to the crisis families in Pakistan have endured. The Hysone tablets are being distributed free of charge to leading paediatric endocrinologists around the country, and records kept of those families who are receiving the medicines (families either sign their names or provide a thumb print in ink if they are not able to write).

The co-ordinated distribution of medicines such as Hysone via doctors across the country will not only save lives, but also help to establish a national register of CAH patients to assist in future planning and action. Thank you Alphapharm for all you are doing to contribute to long-term change for the children of CLIP in Pakistan. 🌸

Collaborative Efforts for Children Living with Diabetes

CLAN and the International Diabetes Federation's Life For A Child (LFAC) program have enjoyed a long-term relationship, stretching back to CLAN's earliest years supporting the diabetes community in Vietnam in 2007. Around this time CLAN was pleased to introduce our colleagues at the National Institute of Child Health (NICH) in Karachi, Pakistan to the wonderful team at LFAC. A strong partnership between NICH and LFAC was developed, and children living with diabetes who are cared for at NICH have been generously supported ever since in their daily struggles to afford essential medicines and equipment.

In November 2014 CLAN was thrilled to attend a Diabetes Club meeting at NICH, and speak with local children and families about their experiences and dreams for the future. A key request emerging from families was for more detailed information on diabetes to be available in Urdu language, and CLAN has since committed to work in partnership with NICH and others to translate the comprehensive resource "Caring for Diabetes in Children and Adolescents" (edited by Geoffrey Ambler and Fergus Cameron) into Urdu.

CLAN would like to formally thank the team at LFAC for their enduring support to the Pakistani Diabetes community. CLAN was proud to formalise our partnership with LFAC in 2015 with a Memorandum of Understanding that will enable CLAN and LFAC to work together more closely for the benefit of children living with diabetes. CLAN was greatly encouraged by our conversations with the families and young people we spoke with in Pakistan. All were optimistic about their future (we learned that there is a future astronaut living in Karachi!), and many remembered the difficult days experienced prior to the support received by LFAC. Thank you LFAC and NICH for your great efforts! 🌸

"We need affordable access to medicine and equipment"





PILLAR TWO: Education, Research and Advocacy

Information is power. Families of children living with chronic health conditions in resource poor settings 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. In our advocacy efforts, CLAN is proud to raise the voices of the children, adolescents, youth and families that we work with to the highest echelons of power.

A New Resource for Families: CH Booklet, Vietnam

Congenital hypothyroidism (CH) is one of the most common paediatric endocrine conditions and without appropriate management has profoundly detrimental impact on the health and development of affected children. Implementation of Newborn Screening (NBS) for CH is vital to the early detection of CH in newborn babies. Once diagnosed, with appropriate treatment and monitoring, children with CH should expect to enjoy a high quality of life and reach their full potential.

In recent years Vietnam has established an effective NBS program for CH, and is now diagnosing increasing numbers of children with this condition. Thanks to generous support from Merck Serono and Prof Maria Craig of The Children's Hospital Westmead, CLAN was proud to work in partnership with doctors from Children's Hospital 2 in Ho Chi Minh City, Vietnam to translate a key educational resource on the management of CH into Vietnamese. CLAN was proud to launch the booklet, with an initial print run of several thousand copies, so that all families of children living with CH in Vietnam might receive a free copy. ✿

Leaving No Child Behind at the 65th Annual UNDPI/ NGO Conference in New York

CLAN (Caring & Living As Neighbours) was proud to attend the 65th Annual United Nations Department of Public Information (UNDPI) Conference for NGOs (Non-Government Organisations) at UN headquarters from 27-29 August 2014 in New York. Titled "2015 and Beyond". The conference was an opportunity for civil society from around the world to come together and contribute to a shared action agenda for future sustainable development.



Seun Adebisi and Laura Musambayi



www.cancer.org

As an Australian NGO officially associated with UNDPI/ NGO, CLAN was thrilled to be accepted to host a Workshop at the conference. Held in the North Lawn Building on 28 August, CLAN's workshop was entitled Empowering Young People to Enjoy Healthy Lives - A Focus on NCDs and Collaborative Action by Civil Society in the Post 2015 Agenda. With thanks to generous funding support from the American Cancer Society (ACS), CLAN was able to harness this unique opportunity to advocate for children, adolescents and NCDs within the post-2015 discourse.

Moderated by Dr Kate Armstrong (President of CLAN), the workshop featured five incredible speakers – Seun Adebisi, Laura Musambayi, Jamal Raza, Maisha Hutton and Rose Rodas – each offering a perspective on the challenges faced by children and adolescents who are living with Non-Communicable Diseases (NCDs) and other chronic health conditions in low-and-middle-income countries (LMICs). Ranging from the personal, to the national, regional and then global focus, the panelists each inspired and informed a captivated audience. ✿

"We need more education, research and advocacy"



The World Cancer Leaders' Summit and World Cancer Congress 2014

Report by
Dr Mellany Murgor,
Nairobi, Kenya

The world cancer leaders' Summit is a highly prestigious event held by UICC and its partners to discuss various aspects of cancer globally.

Last year, the event was held on 3 December 2014 in Melbourne, Australia. I was one of the few young leaders who had the privilege of joining many renowned influential leaders from all over the world during the World Cancer Leaders' Summit, which is an invite only event. My expectations of the Summit were surpassed by a great margin. Coming at a time when I had just completed my medical school training, it marked a great inception into my professional life as a doctor. There was a lot to learn and contribute in the various break-out sessions on investments for Tobacco control, screening and vaccination, radiotherapy, palliative care and National Cancer Control Planning.

The economics involved in cancer control cuts across all sectors and it is one aspect which governments must be made clearly aware of.

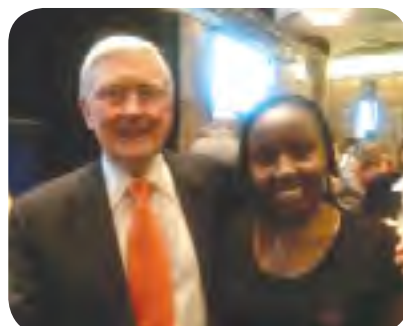
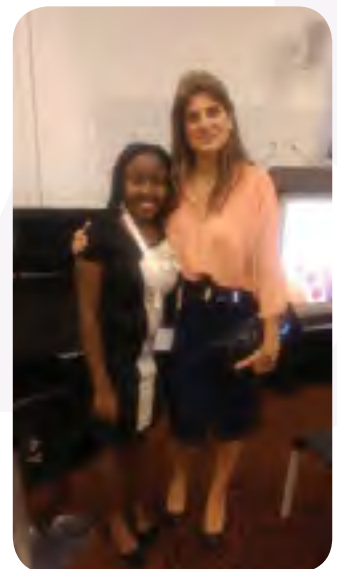
Participating in the rest of the congress sessions was also a great opportunity to learn, the various panel discussions, plenary sessions, the big debate and rapid fire presentations among others had a lot to take home.

Discussions on Non-communicable diseases have become more vibrant in the world and more so in the low and middle income countries where my country currently falls.

Over the past three years I have been involved in creating awareness on cancer among youths and women, carrying out cancer screening and advocacy. Educating women and young girls about cancer has been a great opportunity for me to make the desired change I have always wanted. As it is said empowerment is the key to policy change and a better life. It is my greatest desire to see the young people take charge and be responsible of matters regarding their health.

I was able to join forces with several like-minded people and for sure the progress to curb cancer will surely be accelerated. At the end of the congress, I knew for sure that I was headed in the right direction in the global course of Action against NCDs and Cancer. It was such a rewarding experience. Looking forward to implementing the great lessons learnt. From the networks I made, I have been able to participate in the Global scholars Program by the America Cancer Society to increase advocacy for cancer within my country. Finally it was definitely great visiting the most beautiful city in the world.

The experience will not only live with me, but make an impact to many more that I will come across with. Thanks to the CLAN team for making all this possible. ✨





PILLAR THREE: Optimising Medical Management

If children living with chronic health conditions in resource poor settings are to achieve equitable health outcomes, 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.

OI and DMD Project in Vietnam, July 2014

Update Report by
Dr Sue Ditchfield
(Project Co-Ordinator,
CLAN)

With generous funding from the Australian Embassy in Hanoi, CLAN was able to conduct a comprehensive education and training project in Vietnam for the Osteogenesis Imperfecta (OI) and Duchenne Muscular Dystrophy (DMD) communities. A team from Children's Hospital Westmead supported the project, and was composed of Professor Craig Munns (Paediatric Endocrinologist), Professor David Little (Paediatric Orthopaedic Surgeon), Lucy Kevin (Specialist Genetic Counsellor), Verity Pacey and Kate McIntosh (Paediatric Physiotherapists specialising in OI and DMD).

The project began in Hanoi, where meetings of both the OI and DMD Support Groups were held at the National Hospital of Pediatrics (NHP). Verity and Kate were able to demonstrate various physiotherapy techniques and these were filmed by our great friend and supporter, Thu from C3 Vietnam so that the training could be made available longer term online.

CME (Continuing Medical Education) sessions were held in Hanoi, Hue and Ho Chi Minh City, with establishment of OI and DMD communities at all centres. Thank-you again to everyone involved in this project and particularly to the Australian government for making the entire process possible. ✿



Thanks to APPES and APEG

CLAN was thrilled to receive an invitation from APPES (the Asia Pacific Paediatric Endocrine Society) and APEG (the Australasian Paediatric Endocrine Group) to host a complimentary stall at the first joint APPES/APEG Scientific meeting held in Darwin, Australia from the 29 to 31 October 2014.

Rather than CLAN designing the stall ourselves, we invited local partners from across the region to submit proposals and outline their own vision for running the stall independently. CLAN received an excellent proposal from Dr Tran Trieu Phuong Dong and Dr Nguyen Thi Minh Tan from Children's Hospital 2 (CH2) in Ho Chi Minh City. Sincere thanks must go to Dr Ha Manh Tuan, Director of CH2 for supporting his staff in this venture.

The stall was fabulous with full length posters expressing the work of CH2 in Vietnam and ways their team has integrated the five pillars of CLAN in all they do. Colourful posters told stories of patient and family empowerment and participation; the value of disseminating translated educational resources; a commitment to ongoing health professional development; and the importance of local community support and development as an underlying framework.

Sincerest thanks must also go to two other fantastic people: Ms Irene Mitchelhill for her invaluable support of CLAN and the team from CH2 in the planning of this stall, and for sharing her CAHPepTalk resources so generously with all; and Prof Maria Craig for her ongoing commitment to Paediatric Endocrinology in Vietnam over so many years. Great things happen when we all work together!!

THANK-YOU APPES, APEG and CH2!!! ✿

"All kids need access to good quality health care."



CLAN and APPEs Support Vietnamese Doctors to Attend Fellow School and Meetings in Darwin, Australia

**Report by
Dr Tan Nguyen,
Children's Hospital 2,
Ho Chi Minh City,
Vietnam**

My name is Tan Nguyen, a junior clinician working in department of nephrology – endocrinology in Children's Hospital 2, Ho Chi Minh City, Vietnam.

There have been many programmes from CLAN and APPEs in Children's Hospitals throughout Vietnam. They have both helped us to organise many seminars, workshops, CME events (Continual Medical Education) for the doctors from many specialists. They also have provided many books and booklets for the patients and their parents to let them understand their diseases and to deal with those conditions (for example, Congenital Adrenal Hyperplasia, Diabetes Mellitus and Nephrotic Syndrome).

With the generous sponsorship from both CLAN and APPEs, my colleague and I had the opportunity to participate in the Fellow school and Joint Meeting in November, 2014 in Darwin, Australia. This was the first most significant chance for us to enjoy the professional conference together with many doctors from around the world. Not merely the knowledge, it has also brought us new perspectives in approaching patients and in our attitude to the patients as well. I had my case presentation with Hypopituitarism and my colleague went with his poster on Leydig cell's tumour. We deeply enjoyed studying, discussion about the endocrinology diseases and have established new relationship with many doctors for future cooperation.

The next interesting thing I should mention is about CLAN and my Hospital Booth in the Conference. During those three days, together with Mrs Irene Mitchel-Hill from CLAN, we built our unique booth presenting the images of my hospital, the activities of CLAN and, of course, our cooperation and interaction in helping children with chronic conditions. We had the chance to meet and speak with many colleagues from other countries about our work and invite them to join the activities of CLAN. We hope we have spread the invaluable spirit of CLAN to a wide range of regions.

Last but not least, also in the last three months of 2014, we were working hard to launch the new booklet of Congenital Hypothyroidism within our Children's Hospital in Vietnam from the great help and promotion of CLAN. Doctor Kate and Professor Maria from University of Sydney have continuously supported us to have the booklet sent out to many parents and patients with congenital hypothyroidism. We appreciate their enthusiasm and long term commitment.

In my very last words, I would like to give my special thanks to CLAN for all spectacular activities they have done for our children and our country. I do wish for all of CLAN's endeavours to fulfill great achievements in all aspects. 🍀





PILLAR FOUR: Encouraging 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!

Children and Families Living with Lupus in Vietnam Join the International Lupus Community

Lupus is an auto-immune disease that can be hard to manage in high income countries. So for children and their families in low- and middle-income countries a diagnosis of Lupus is devastating and isolating. In 2015, health professionals and families in Vietnam came together around World Lupus Day (10 May 2015) to celebrate their rightful place within the International Lupus Community, and CLAN would especially like to acknowledge the generosity of the Lupus Association of NSW, the Australian Embassy of Hanoi and Dr Elizabeth Hodson for their incredibly generous support and encouragement of this community.



Bringing the Lupus Community together for annual meetings has been a hugely important part of the change that health professionals have witnessed in Vietnam for children with Lupus, with reduced admissions and better outcomes clearly demonstrated, as well as no families deserting treatment for their children now that they feel more encouraged, empowered and supported to fight for their children's health.

Attendance at the Lupus Club meeting by a representative from the Australian Embassy in Hanoi was especially inspirational, and CLAN would sincerely like to thank Ambassador Hugh Borrowman and his team for strengthening our work in Vietnam. As an Australian NGO we are proud to identify as Australians in the work we do internationally, and having the support of the Australian Embassy means so much not only to CLAN, but also the families and staff working so hard to drive change. ✨

Connecting with CAHSAPI in the Philippines - Learning from Youth Living with CAH

In June 2015, CLAN was very grateful for the opportunity to visit Philippines General Hospital (PGH) in Manila, and meet with long-term friends, colleagues and supporters of CAHSAPI, the Congenital Adrenal Hyperplasia (CAH) community in the Philippines. PGH is the largest charity government hospital in the Philippines, and CLAN has been proud to collaborate with Dr Sioksoan Chan Cua and CAHSAPI since 2005.

An informal youth gathering was held on 19 June in a private room of the hospital, and five young people who are living with CAH (one Australian and four Filipino) – together with their families and some of the wonderful and caring health professionals at PGH – came together to talk about life with CAH and compare experiences between Australia and the Philippines. An additional Filipino young person was unable to attend in person because of school commitments, but was represented by their parent in discussions. The age of the youth participating ranged from nine to 26 years of age, with two boys and four girls represented in total.

The achievements of the Philippines in terms of implementing newborn screening (NBS) for CAH nationwide was acknowledged in discussions amongst families and doctors, with one of the young people attending the meeting actually being the first baby diagnosed with CAH through NBS in the Philippines when it first started 19 years ago! Australia's complete failure to implement NBS for CAH was met with disbelief by all present.

All attending expressed their profound gratitude to the staff of PGH for their care and commitment to children and young people living with CAH in the Philippines – particularly their care for the poorer families. The annual CAHSAPI Lay Forums, held in November each year and sponsored by the NBS program, are an excellent opportunity to provide more detailed education for newly diagnosed CAH families from across the Philippines, and were generally regarded as a great success for the Filipino CAH community as a whole.

All young people attending were leading active lives and enjoying school and/or university studies. Sport was identified as a positive in most peoples' lives, helping them stay fit, active and healthy. Facebook is an effective means of communication for members of the CAHSAPI Community, and helps everyone stay connected, share Florinef and other information. ✨



"Family support group meetings help us a lot"



Media attendance at Wishbone Day Saves the Lives of Children with OI in Pakistan!

Excerpts from a report by Dr Yasir Khan



This year the National Institute of Child Health (NICH) partnered with CLAN (Caring & Living as Neighbours) on 6 May 2015 to commemorate Wishbone Day, an International Awareness Day for Osteogenesis Imperfecta (OI). The event was attended by 25 families of patients with OI, our endocrine team, media reporters and a representative from the Australian Embassy. NICH and CLAN would like to sincerely thank Australia's Consul to Karachi, Mr Farrukh Ikram for his involvement in this special day - it was a huge morale boost for families, staff and CLAN alike to have Australia's strong support for children living with OI in Pakistan!

There are very few treatment options available for OI patients in a developing country like Pakistan. OI in Pakistan is mostly misdiagnosed and mismanaged. There are few tertiary centers that provide OI patients with the latest treatment options available that are freely available for OI patients belonging to other developed countries.

Presently NICH is offering up-to-date treatment strategies for patients registered in our outpatient department. This includes intravenous Injection Zoledronate and Fassier-Duval telescopic rods.

Zoledronate is a bisphosphonate which increases the bone density of OI patients, therefore remarkably decreasing the incidence of bone fractures.

Fassier-Duval telescopic rods are revolutionary rods which are implanted during surgery and help in straightening the leg bones of these patients. NICH presently has over 60 patients registered with us and these up-to date revolutionary management strategies are offered to all our patients free of charge.

This year for the first time in Pakistan we united with OI patients from all over the world to celebrate Wishbone Day. We were part of the International Wishbone Day Celebrations on Facebook and Twitter.

The target of Wishbone Day is to create awareness of OI for health care professionals and the general public alike that OI is a manageable non-communicable disease and latest treatment is available in a developing country like Pakistan.

The colour yellow has been chosen internationally because yellow is the colour of promise and hope. Yellow shines the brightest even when there is little light and where there is hope there is always a way forward.

Surprisingly in the very next OPD, a new patient previously undiagnosed visited us. The parents had seen the TV report on Wishbone Day and were concerned that their child might have OI. 🌸



Australian Hon Consul and Prof Jamal Raza

WISHBONE DAY
is celebrated every
year on 6 May by
the International
Osteogenesis
Imperfecta community





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 settings. 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.

A young man living with CAH in Australia is inspired by the story of a young man living with CAH in Pakistan

Reflections on an interview by Katie Hunsberger – CLAN Intern June to August 2015

Hearing the story about a young man living with CAH in Pakistan was both sobering and inspirational. There were three things that stood out: the complete difference in how CAH has impacted Salman's life; how living with CAH has shaped the sort of person Salman is, and how he is using his condition to be able to affect change in Pakistan.

In a high-income country with access to medicine, testing facilities and support networks children are "living" with rather than "suffer" from CAH. It is sad to hear how this young man had so many questions when he was younger about how to deal with CAH. Information was limited and access to medicine – Hydrocortisone and Fludrocortisone was poor.

Bullying and the stigma associated with a non-communicable disease (NCD) such as CAH resulted in an unjust isolation that has been endured throughout this young person's life. While typical teenage issues of self-consciousness and a lack of self-confidence is understandable, having an NCD can alienate people even further.

Awareness was a key theme that was spoken about – awareness amongst friends and teachers as to what CAH and NCDs are and how living with NCDs affects a person; the need to raise awareness within the Pakistani community about the need to better educate and care for people living with NCDs; and the value of raising awareness within CAH communities so people know how to live with CAH so it doesn't influence their lives to a serious and detrimental effect.



No, this young person is also asking questions about the future of NCDs in Pakistan and how to draw the community closer and together abolish the stigmas around NCDs. He is committed to raising awareness about issues in the community, and believes that in time these efforts will generate change. ✿

Encouraging children living with chronic health conditions to attend school

"We are poor - my family needs financial security"



From our earliest consultations with parents of children and young people living with chronic health conditions in resource poor settings, CLAN has appreciated the enormous financial burdens that can devastate these families. Not only are the burdens felt keenly by parents, but children and young people often feel guilty for causing financial strains for their families.

One sustainable long-term solution that CLAN has committed to is encouraging families, health professionals and partners to engage in every effort to ensure all children living with chronic health conditions are attending school and completing their education to the best of their ability. There can be many barriers that prevent a child living with a chronic condition from attending school: financial burdens can make attendance at school impossible; parents may unnecessarily fear sending their children to school in case they get sick; children and young people try to avoid bullying and social isolation; teachers and schools can make children with special needs feel unwelcome; and shame and stigma are all too frequently identified as further reasons children miss school.

CLAN consistently encourages our communities to focus on positive messaging around attendance at school for children living with chronic health conditions and welcome ever increasing awareness around the importance of disability inclusive approaches that make an education achievable for EVERY child. ✿



Dr Elisabeth Hodson presents children living with Lupus in Vietnam awards in recognition of their great efforts at school)

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 Executive members and a variable number of general committee members who are involved in project work for CLAN. Executive positions are voted on at each Annual General Meeting as per the Constitution.

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

CLAN Funding

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

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

Website: www.clanchildhealth.org

E-mail: info@clanchildhealth.org

Post: CLAN Inc
PO Box 996
TORONTO NSW 2283



@clanchildhealth



www.facebook.com

CLAN FINANCIALS

Committee's Report for the Year Ended 30 June 2015

Your committee members submit the financial accounts of the CLAN (Caring And Living As Neighbours) Incorporated for the financial year ended 30 June 2015.

Committee Members

The names of committee members at the date of this report are:

Dr Kate Armstrong B Med, DCH, MPH

Dr Boonseng Leelarthaeapin PhD, BSc, Dip Nut Diet

Laura Healy LLB, BMus, LLM

Heidi Armstrong BSc, LLB

Robert Armstrong

Kelly Leight

Catherine Cole JP

Dr Sue Ditchfield

Dr Yen-Thanh Mac MD

Valerie Foley

Amy Eussen

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:

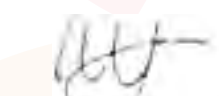
Year ended 30 June 2015

Year ended Prev Year End

\$86,479

(\$110,887)

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



Dr Kate Armstrong
Committee Member



Catherine Cole
Vice President and Secretary

Independent Auditor's Report to the Members for the Year Ended 30 June 2015

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 2015.

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 2015 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
WP Partners
34 Main Road
BOOLAROO NSW 2284

Income and Expenditure Statements for the Year Ended 30 June 2015

	2015 (\$)	2014 (\$)
Income		
Donations and Gifts		
Monetary		
- Corporate Donations	7,000	10,387
- Personal Donations	16,375	21,737
- Gofundraise	401	-
- Non-Monetary	-	-
- Bequests and Legacies	-	-
Grants		
- AusAid	-	-
Other Australian	-	-
- Medtronics Grant	-	5,269
- DFAT	76,839	9,500
- Diabetes NSW	34,513	-
Other Overseas		
- NCD Child Projects	41,911	-
- Neph Cure	10,391	-
- UNDP/NGO	20,864	-
- Medtronics Grant	-	22,000
- Save the Children	-	5,330
- AZ/YHP Grant	-	82,141
Investment Income		
- Westpac Interest	651	2,016
Other Income		
- Members' Subscriptions	300	273
Revenue for International Political or Religious	-	-
Total Income	209,245	158,6538

Expenses

International Aid and Development Programs Expenditure		
International Programs		
- Consultants' Fees	-	94,991
- Overseas Medication	-	510
- Overseas Training	-	1,203
- Overseas Hospitals	8,520	28,879
- Overseas Travel/Accommodation	3,131	2,558
Funds to International Programs		
- Program Support Costs	-	-
- Community Education	-	-
- Fundraising Costs	-	-
- Public	-	-

	2015 (\$)	2014 (\$)
Expenses – Continued		
Government, Multinational and Private		
- Accountability and Administration	-	-
- Accountancy	3,159	2,280
- Advertising and Promotion	-	4,080
- ACFID Fees	-	-
- Bank Charges	403	541
- Computer Expenses	150	-
- Conference Fees	-	17,585
- DAP Vietnam Grant Expenses	5,662	-
- Depreciation	796	838
- General Expenses	110	2,149
- GoFundraise Fee	300	-
- Insurance	2,595	2,613
- Legal Fees	-	2,108
- NCD Child Conference	37,149	69,841
- UNDP/NGO Expenses	24,181	-
- Diabetes NSW Expenses	31,902	-
- Printing and Stationary	3,010	7,245
- Subscriptions	1,626	2,653
- TeleConferences	72	8,206
- Travel, Accommodation and Conference	-	11,522
- Web Design	-	9,738
- Non-Monetary Expenditure	-	-
Total International Aid and Development Programs Expenditure	122,766	269,540
International Political or Religious Adherence Promotion Programs Expenditure	-	-
Domestic Programs Expenditure	-	-
Total Expenses	122,766	269,540
Profit From Ordinary Activities Before Income Tax	86,479	(110,887)
Income Tax Revenue Relating to Ordinary Activities	-	-
Net Profit Attributable to the Association	86,479	(110,887)
Total Changes in Equity of the Association	86,479	(110,887)
Opening Retained Profits	23,876	134,763
Net Profit Attributable to the Association	86,479	(110,887)
Closing Retained Profits	110,355	23,876

CLAN operates on a cash basis and has no liabilities to report.

The accompanying notes form part of these financial statements.

Income and Expenditure Statements for the Year Ended 30 June 2015

	Notes	2015 (\$)	2014 (\$)
Current Assets			
Cash and Cash Equivalents	2	108,780	18,127
Trade and Other Receivables		804	4,182
Inventories		-	-
Assets Held for Sale		-	-
Other Financial Assets		-	-
Total Current Assets		109,584	22,309
Non-Current Assets			
Trade and Other Receivables		-	-
Other Financial Assets		-	-
Property, Plant and Equipment	3	771	1,567
Investment Property		-	-
Intangibles		-	-
Other Non-Current Assets		-	-
Total Non-Current Assets		771	1,567
Total Assets		110,355	23,876
Current Liabilities			
Trade and Other Payables		-	-
Borrowings		-	-
Current Tax Liabilities		-	-
Other Financial Liabilities		-	-
Provisions		-	-
Other		-	-
Total Current Liabilities		-	-
Non-Current Liabilities			
Borrowings		-	-
Other Financial Liabilities		-	-
Provisions		-	-
Other		-	-
Total Non-Current Liabilities		-	-
Total Liabilities		-	-
Net Assets		110,355	23,876

	Notes	2015 (\$)	2014 (\$)
Equity			
Reserves		-	-
Retained Profits		110,355	23,876
Total Members' Funds		110,355	23,876
Cash Flow From Operating Activities			
- Receipts from Customers		211,972	158,653
- Payments to suppliers and employees		(121,970)	(273,386)
- Interest received		651	2,016
Net Cash (Used in) Operating Activities (Note 2)		90,653	(112,717)
Purchase of Plant and Equipment		-	(2,186)
Net Cash (Used in) Investing Activities		-	(2,186)
Net Increase (Decrease) in Cash Held		90,653	(114,903)
Cash at the Beginning of the Year		18,127	133,030
Cash at the End of the Year (Note 1)		108,780	18,127

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 Donations	11,847	8,340
CLAN Fund	1,047	3,369
CLAN Fund Interest	95,886	6,418
	108,780	18,127

NOTE 2: Reconciliation of Net Cash Provided By/Used in Operating Activities to Net Profit

Operating Profit (Loss) After Tax	86,479	(110,687)
Depreciation	796	838
Changes in assets and liabilities net of effects of purchases and disposals of controlled entities:		
Increase (Decrease) in Sundry Provisions	3,378	(2,668)
	90,653	(112,717)

CLAN operates on a cash basis and has no liabilities to report.

The accompanying notes form part of these financial statements.

Income and Expenditure Statements for the Year Ended 30 June 2015

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 incidental 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 residual 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 which 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 2015

NOTE 2: Cash Assets	2015 (\$)	2014 (\$)	NOTE 3: Property, Plant and Equipment	2015 (\$)	2014 (\$)
Bank Accounts			Leased plant and equipment		
CLAN Donations	11,847	8,340	At Cost	6,649	6,649
CLAN Fund	1,047	3,369	Less: Accumulated amortisation	(5,878)	(5,082)
CLAN Fund Interest	95,886	6,418		771	1,567
	109,584	22,309			

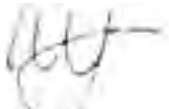
Statement by Members of the Committee for the Year Ended 30 June 2015

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 2015 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 and Secretary

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 3 December 2015.
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
Vice President and Secretary

NGUYỄN XUÂN ĐOÀN

What Would Đoàn Say?

In August 2014, CLAN was proud to host a Workshop at the 65th Annual United Nations Department of Public Information (UNDPI) Conference for NGOs at UN headquarters in New York. Titled “2015 and Beyond”, the conference was an opportunity for civil society from around the world to come together and contribute to a shared action agenda for future sustainable development.

It was an incredibly successful event ... Our incredible speakers shared their powerful stories and insights; we influenced the Conference Declaration and Resources Documents, introducing strong language to support future advocacy efforts; we participated in a strategic and fun social media advocacy campaign (see the NCD+vine campaign!); and we had the opportunity to come together as a community that cares, renewing our commitment to further action that helps young people living with NCDs and other chronic health conditions around the world to enjoy the highest quality of life possible.

An inspiration to the DMD Community of Vietnam

Nguyễn Xuân Đoàn was a young man living with Duchenne Muscular Dystrophy (DMD) in Vietnam. A University graduate with a passion for IT, Đoàn was the internationally respected inaugural President of Vietnam's first DMD Club (established in 2013). An inspiration to the 200+ families who are now members of the DMD community and a hero to every young boy living with DMD in Vietnam, Đoàn passed away on 1 September 2014.

Đoàn's incredible story was featured in the story booklet CLAN was proud to launch at the 65th UNDP/NGO Conference. Titled "Leave No Child Behind", the booklet featured young heroes working internationally, giving a voice to the many young people and NCD communities living with chronic health conditions around the world. Đoàn's story featured a photo of Đoàn meeting with the Australian Ambassador to Vietnam, His Excellency Hugh Borrowman, and showcased the progress he was making for his community in sharing messages about the needs and challenges of children with special health needs in Vietnam.

Reflecting on CLAN's participation in the UNDP/NGO Conference, it's timely to consider what our efforts all mean in the light of Đoàn's loss.

As CLAN prepared for the conference there is no doubt we had Đoàn's full support and encouragement. Đoàn was an inspiration for all communities living with disability in Vietnam (such as the Osteogenesis Imperfecta (OI) - or Brittle Bone - Community) and he supported any efforts that might help ensure no child was left behind in the post-2015 agenda. In one of his last emails to CLAN, Đoàn wrote:

"This is one great opportunity for the international community to better understand the DMD community and OI in Vietnam. Congratulations CLAN (will be) involved in this meaningful conference of the United Nations ... I wish you would have more success at the conference. Thank you very much for great things you bring to us!"

Đoàn helped CLAN to believe in the importance of gathering together as united members of civil society to speak up and continue our collective efforts for children and adolescents who are at risk of, living with and affected by NCDs in LMICs. Đoàn believed strongly that EVERY child matters.

Sadly, we never had the opportunity to share with Đoàn details of the conference, and as we reflect on the 65th Annual UNDP/NGO Conference it's timely to ask ourselves ... what would Đoàn say about it all? Would Đoàn be happy with everything achieved at the UNDP/NGO Conference? What advice would he have for us moving forward?

Undoubtedly, Đoàn would have been inspired by the incredible speakers we had participating in the CLAN Workshop. I believe he would have been encouraged and grateful that the world was given the opportunity to hear stories of struggles – and victories! – so very similar to those experienced by his own DMD community in Vietnam.

Đoàn would have been encouraged by the changes made in the Conference Declaration and Resources Documents as a result of the collaborative advocacy efforts CLAN undertook with others. In particular: the specific inclusion of children's rights; the call for Universal Health Coverage for all; and the need for a focus on NCDs in the post-2015 health agenda would all have resonated with Đoàn. Đoàn would have approved of our efforts to engage with others through social media – although as the IT guru he was, Đoàn would certainly have had advice for us on how we could tweak efforts for next time! He would have been proud to know his DMD Community in Vietnam is now a beacon of hope for EVERY child living with DMD around the world.

Thank you Đoàn. Thank-you for everything you taught us. 🌸

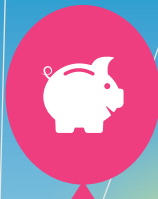


Held on 19 April 2015 (to coincide with Vietnam Disability Day on 18 April), CLAN was proud to support a day of celebration, bringing together family and friends of Nguyễn Xuân Đoàn



Leave No Child Behind

MEET THE CHALLENGE



#YouthVoices

#CommunityEmpowerment

#Equity



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