



CARING & LIVING AS NEIGHBOURS

Annual Report

July 2011 – June 2012



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



ACFID
MEMBER

ABOUT CLAN

What is CLAN?

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

CLAN's Vision

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

CLAN's Mission

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

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:

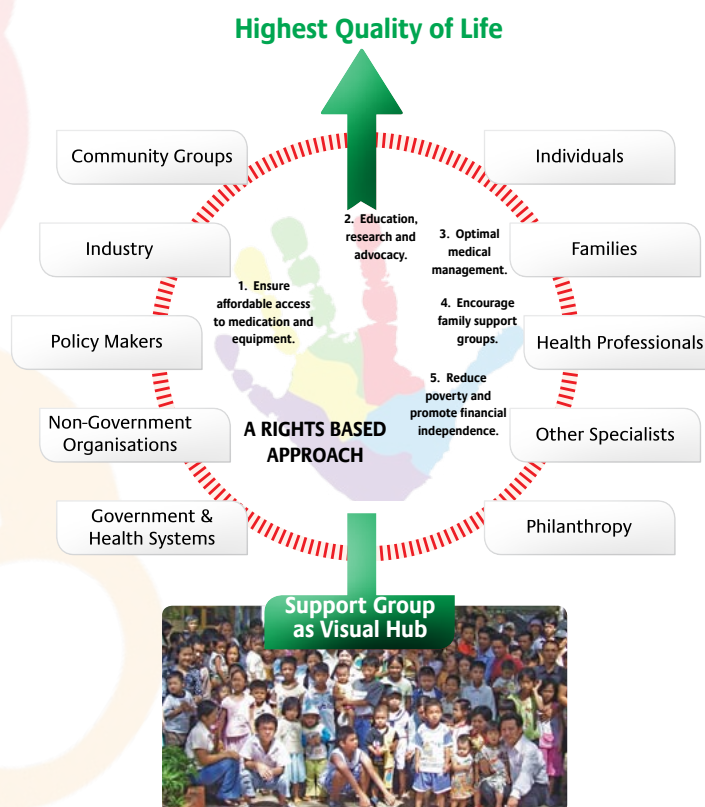
1. Affordable access to medicine and equipment
2. Education (of children, families, health professionals, policy makers, national and international communities), research and advocacy
3. Optimisation of medical management (holistic care; primary, secondary and tertiary prevention)
4. Encouragement of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

At all times the community of children remains the central focus. This ensures the children's 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 Framework for Action

Our mission is to maximise quality of life for children (and their families) who are living with chronic health conditions in resource-poor countries of the world



A community of children, Hanoi 2007. All children in this photo have the same chronic health condition and their families meet regularly for support.

PRESIDENT'S REPORT

Grass Roots to the United Nations

Dr Kate Armstrong



As a medical practitioner, public health enthusiast and mother of a child with a chronic health condition, Kate brings a broad knowledge base to her role as President of CLAN, which she founded in 2004.

Graduating from medical school in 1993, Kate has since worked in a variety of clinical and public health roles, and is currently completing her Doctorate of Public Health.

Reflecting on all that has been achieved in this last year, two things become very clear: firstly, a LOT is now happening for children and their families who are living with chronic health conditions in resource-poor countries; and secondly, the scale of this activity is only possible because of the broad range of partners involved.

It is exciting to see so much happening – and important to remind ourselves that it is not before time. It is an inescapable fact that in low- and middle-income countries the voices of children and young people (and their families) who are living with chronic health conditions have for too long gone unheard, and the enormous global inequity experienced has gone largely unnoticed.

So the fantastic achievements and strong partnerships reflected in this annual report give us reason for optimism ... times are changing.

Globally, the September 2011 United Nations High Level Meeting on Non-Communicable Diseases (NCDs) has drawn a line in the sand for us all. This landmark event focused international attention on the prevention and management of chronic disease. In collaboration with a broad range of partners CLAN is privileged to be a part of the growing NCD Child movement, and will continue to do all we can to ensure children and adolescents are meaningfully integrated within the broader international non-communicable disease (NCD), health and development discourse.

At a grassroots level too, CLAN will continue to work in partnership with others to inaugurate and strengthen communities of children and their families who are living with chronic health conditions in resource-poor settings. As a small Australian-based non-government organisation (NGO) that started back in 2004 with the goal of helping children with a relatively unknown chronic health condition (Congenital Adrenal Hyperplasia – CAH), it is rewarding now to see that the strategic framework for action that CLAN developed all those years ago has been successfully transferred to a range of other chronic conditions, countries and cultures. CLAN's framework for action (our '5 Pillars') emerged from consultation undertaken with the CAH community in Hanoi, Vietnam in 2005 and as we approach 2015 it is worth noting that listening to the voices of the children, young people and families living with chronic health conditions is proving as important, powerful and relevant to CLAN now as it was back then.

Indeed, as we continue to focus on a rights-based, multi-sectoral approach to building, strengthening and connecting communities of children, adolescents and families who are living with (and are at risk of) chronic health conditions, it is vital CLAN maintains those living in resource-poor settings as the visual hub of all that we do, and strive to ensure their voices inform all that we say. Only in this way will CLAN see our vision of equity for our neighbours' children achieved.

Sincerest thanks to everyone who has been a part of this incredible journey so far... The contribution of each and every person has been invaluable. Together we are STILL making a difference.

Yours sincerely
Kate Armstrong



Nephrotic Syndrome Club meetings offer children and families a chance to share their voices

CLAN OFFICE BEARERS



Vice President – Cath Cole

Cath Cole has been the Secretary for CLAN since 2007 and was elected Vice President at the Annual General Meeting in November 2011. Cath has enjoyed a long career in government and has developed skills in a number of areas which she brings to CLAN including policy development; project management; program development; and development and delivery of education and training; preparation of foundational documents such as strategic and business plans.

"Congratulations to the CLAN team, who in this reporting year have driven CLAN from strength to strength as it has reached out further and deeper to help those in need." ✿



Treasurer – Heidi Armstrong

Heidi Armstrong is the Treasurer of CLAN and is a qualified legal practitioner. Heidi no longer practices law, instead she runs the mortgage management business, State Custodians Mortgage Company. In this role Heidi directs the business activities of providing residential home loans to borrowers Australia wide. Heidi is a full member of the Mortgage & Finance Association of Australia and as the director of State Custodians, she has had to pass rigorous background checks including police, credit, audit and business reference checks to operate as a mortgage manager. Heidi uses her skills in running a business to assist CLAN in managing its financial affairs. ✿



Secretary – Boonseng Leelarthapin

Boonseng Leelarthapin is the Secretary of CLAN. Boonseng worked in the higher education sector for more than thirty years, and has obtained a PhD (cardiovascular disease and nutrition) from University of New South Wales. Having volunteered for the position of Executive Assistant with CLAN in 2010, he brought with him years of experience in the Higher Education sector and excellent research and administration skills. Boonseng's value to CLAN was quickly recognised and he was elected as Secretary of CLAN at the 2011 Annual General Meeting. Boonseng has been instrumental in contemporising CLAN's foundational documents and grant applications. Boonseng keeps abreast of development in the not for profit sector and government regulation regularly attending ACFID meetings and workshops. ✿



Public Officer – Valerie Foley

Valerie Foley is the mother of a child with autism and the author of *The Autism Experience – International Perspectives on Autism Parenting*. When she's not working on awareness raising and advocacy projects in the local autism community, she writes children's television programs. Working with Autism CLAN has been nothing short of a privilege for Valerie, and the highlights have included the Vietnamese recording of *Through My Eyes*, witnessing the growing acceptance and awareness of autism in Vietnam and seeing Australian peak autism bodies recognise and support CLAN's initiatives. ✿

CLAN ENGAGES IN GLOBAL NCD ADVOCACY

CLAN Attends United Nations High-Level Meeting on NCDs

CLAN and the Child Focused Working Group (CFWG) of the NCD Alliance returned to New York City on 19 and 20 September 2011 to take part in the United Nations High-Level Meeting (UNHLM) on Non-Communicable Diseases (NCDs). CLAN was fortunate to have been one of only two Australian NGOs invited to attend the General Assembly meetings. It was an exciting couple of days, with member states such as Australia, making concrete commitments to addressing the challenges posed by NCDs. Amy Eussen attended the Opening Plenary of the High-Level Meeting in the General Assembly and Dr Armstrong attended Roundtable 2, titled "Strengthening national capacities, as well as appropriate policies, to address the prevention and control of NCDs".

During the time in New York City, CLAN also attended a variety of side-events being held. These included one hosted by the WHO entitled "What gets measured, gets done"; the NCD Alliance NGO Briefing and de-briefing "From Advocacy to Action"; the Global Health Council event "Tackling NCDs: How Can Existing Platforms Be Leveraged?"; WHO & UNAIDS UN Side-event on HIV and NCDs: "Achieving Health Equity: Uniting around a common agenda to address NCDs and HIV" and an event on "NCDs and the Law". ✿

CLAN Attends NCD Youth Forum

CLAN was proud to participate in the event "Forum for Action: Building a Youth Movement for NCDs", convened by AYUDA (American Youth Understanding Diabetes Abroad) and YPCDN (Young Professionals Chronic Disease Network) at Weill Cornell Medical College in New York. Participants included the Institute of Medicine, the Population Reference Bureau, the International Federation of Medical Students Associations, GlobeMed, ProCor, CLAN, Student Global ADIS Campaign and Eminence and perspectives from young people living with NCDs from Ecuador and the United States.

Two key highlights of the event were the laughing yoga (fantastic!) and a Skype video interaction between participants in New York and young people living with Diabetes in Ecuador, which made the experiences of those living with NCDs in resource-poor settings very real for everyone! ✿



Delegates at UN side event Skyping with young people who are living with Diabetes in Ecuador

CLAN Supports Australian Anti-Tobacco Efforts

Dr Kate Armstrong attended the presentation by the Hon Nicola Roxon MP at the Nossal Institute in August 2011 and then again in Roundtable 2 at the UNHLM on 19 September. CLAN congratulates the Minister for dealing with an extremely important public health issue in a bold and courageous manner which has gained her international respect.

CLAN used this unique opportunity of connecting with the Australian Health Minister to again lobby for assistance in resolving the long term need to introduce Newborn Screening (NBS) for Congenital Adrenal Hyperplasia (CAH – admittedly a lesser known NCD!) in Australia. By comparison, every single state in the US now screens for CAH, New Zealand have long screened for CAH and our neighbours in the Philippines and Vietnam also screen.



Nicola Roxon addresses member states at a Roundtable discussion at the UNHLM on NCDs, September 2011

CLAN will continue to advocate for CAH NBS and greater equity for Australian babies. ✿

EFFORTS FOR CHILDREN & ADOLESCENTS

Introducing NCD Child

Following on from the UNHLM on NCDs in September 2011, the wide network of organisations and individuals engaged in the Child Focused Working Group (CFWG) of the NCD Alliance were keen to continue advocacy efforts, despite the Terms of Reference for this working group closing. CLAN was pleased to develop NCD Child (www.ncdchild.org) as a new platform for continued advocacy and action towards the integration of children and adolescents within the global NCD, health and development discourse. ✿

CLAN Connects in Different Ways

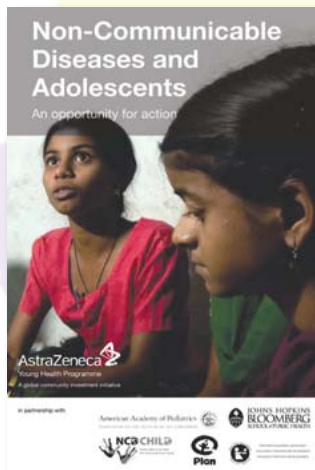


CLAN embraced social media to promote the messages and efforts of the NCD Child movement, and had a strong presence on Twitter at @NCDChild and @clanchildhealth. NCD Child and CLAN are also available on Facebook at www.facebook.com/NCDChild and www.facebook.com/clanchildhealth. NCD Child updates are regularly available at www.ncdchild.org. Find out more about CLAN's activities at www.clanchildhealth.org

Printed materials are another priority for NCD Child and we were proud to collaborate with Johns Hopkins Bloomberg School of Public Health and a range of other members of the NCD Child Network on the development of a booklet resource specifically exploring the field of NCDs and Adolescence ahead of the UNHLM on NCDs.

Titled *Non-Communicable Diseases and Adolescents – An Opportunity for Action* this booklet was an important first step towards clarifying the specific need to focus on adolescents within national programmes for NCD prevention. This novel resource recognised that not only are adolescents affected directly by NCDs, but that future NCD prevention strategies that focus on risk behaviours during this period of life are going to be essential to success. The booklet was widely distributed at events around the time of the UNHLM on NCDs and proved a powerful advocacy tool for the expanding NCD Child network.

The NCD Child Community also came together to write a consensus document on how to effectively prevent NCDs across the life course with specific focus on the key learnings from the communicable disease experience and was launched at the 2012 Commonwealth Health Ministers' Meeting in Geneva. The document entitled "Effective Prevention Strategies for NCDs Targeting Children and Youth: Learning from the CD Experience" can be found at www.commonwealthhealth.org/wp-content/uploads/2012/05/95-99.pdf ✿



Committee Member Profile: CLAN Education and Research Officer

Dr Yen-Thanh Mac



Dr Yen-Thanh Mac was working as a Pediatrician at Children's Hospital One (CH1) in Ho Chi Minh City, Vietnam, and became aware of the work CLAN was undertaking for the Congenital Adrenal Hyperplasia (CAH) and Diabetes communities. Having experienced first hand the challenges facing children who are living with chronic health conditions in Vietnam, Yen-Thanh became deeply interested in the work of CLAN, and has stayed actively engaged ever since.

In her role as Education and Research Officer, Yen-Thanh has contributed enormously to the success of our project work. She has been engaged in the development and translation of key educational resources; research assistance; management of CLAN's social media; and general support roles.

Yen-Thanh has established NCD Child on Twitter (@NCDChild) as one of the strongest international voices for a life-course approach to NCDs. Indeed, @NCDChild had many interesting conversations through Live chat with many organisations all over the world such as UNICEF Australia, UN Development, Medtronic NCD, C3 Collaborating for Health, Every Woman Every Child, UN Youth Australia, Public Health Institute, NCD Alliance, Preserving the Future of Newborn Screening, and other great partners working to promote the voice of children and adolescents within the Non-Communicable Diseases (NCDs) discourse.

Yen-Thanh found advocacy in the Paediatrics field to be especially rewarding, as the need is more compelling where children lack the political and social clout to advocate for themselves. ✿

NCD CHILD CONFERENCE – MARCH 2012

Putting Children and Adolescents on the Global Non-Communicable Disease Agenda

With a view to maintaining the momentum behind advocacy efforts for children and adolescents within the NCD, health and development discourse, the inaugural NCD Child conference was co-convened by CLAN, the Public Health Institute (PHI) and Global Health Council (GHC). Held over two days, the conference was attended by more than 80 representatives of nonprofit organisations, for-profit corporations, advocacy organisations, academic and resource institutions, UN agencies, intergovernmental organisations and health care providers. A third and final strategic planning day was conducted on Wednesday, 21 March 2012 with a small cohort of specially invited delegates.

This conference would not have been possible without the commitment and support of Medtronic Foundation, LIVESTRONG, The California Endowment, Will Organise and the NCD Alliance. Especial thanks to the NCD Child Steering Committee and Consultants for their commitment to the conduct of the conference – through their extensive professional networks the inaugural NCD Child Conference was able to attract esteemed guest speakers and participants representing the best of the health and development landscape.

The conference was deliberately structured to deliver ample opportunities for participation and dialogue, as well as presentation of abstracts and posters. Interactive workshops conducted throughout the conference covered topics such as: learning from the field; access to essential medicines; health system strengthening; effective prevention strategies; and learning from other movements. Within this context, conference delegates were actively encouraged to focus on a number of cross-cutting issues, including: rights-based approaches to child and adolescent health and NCD action; linking with existing platforms; sustainability and scalability; multi-sectoral engagement; addressing the social determinants of health; and maintaining a focus on prevention.

The conference was very much outcomes focused, and proudly delivered all key objectives:

1. *A critical analysis on the Political Declaration from the UNHLM on NCDs as it relates to children and adolescents* – This was presented by Dr Sue Henshall.
2. *A roadmap for governments and organisations in addressing the needs of children and adolescents in the prevention and control of NCDs, including recommendations of programs and policies that can be implemented* – The Oakland Statement was accepted by acclamation on Day Two of the conference and contains specific recommendations on programs and policies that must be implemented if we are to see sustainable and scalable change moving forward.
3. *Enhanced literature base for future research and project work (abstracts for publication, reports, and new forums for ongoing efforts)* – Twenty two abstracts covering a range of challenges and opportunities relevant to the NCD Child Network were submitted and included in the conference report.
4. *Workshops to formulate practical solutions that will deliver tangible improvements in child health internationally (particularly in low- and middle-income countries)* – The conference process created the opportunity for new information, concepts and experiences to be captured in the conference report. Workshops drew on the wisdom and experiences of experts from around the world. Success stories from the field continue to be collated post-conference and disseminated amongst the NCD Child community utilising the NCD Child website and social media platforms.
5. *Recommendations on next steps towards effective monitoring and evaluation of future NCD efforts, and how child and adolescent focused NCD efforts might be integrated within existing platforms, including the Millennium Development Goals review in 2015.* The conference launched NCD Child as a 'movement' with a clear mandate as an invaluable international platform for advocacy and action.

Below: Dr Kate Armstrong

Centre: Wendy Baldwin

Top Right: Sir George Alleyne during his opening address



OAKLAND, CALIFORNIA

Day 3: Strategic Planning for NCD Child



At the Day 3 strategic planning session, CLAN recommended that the time had come to move beyond NCD Child being “a project managed by CLAN” and establish a more formal, transparent, sustainable entity that will continue to drive advocacy and action long into the future.

CLAN agreed to stay on as secretariat in a pro bono capacity over the following six months provided there was a commitment that firm efforts would be undertaken in this time to identify funding for the key roles to continue in a paid capacity beyond September 2012.

In the strategic planning process, CLAN asked that the principles that have grounded CLAN and NCD Child efforts to date be maintained wherever possible:

- a rights-based approach
- love of neighbour driving a passion for justice and equity
- recognition of the intense and overwhelming love parents have for their children and how powerful this can be when parents are empowered
- that grass-roots family support communities remain our visual hub, ensuring their meaningful engagement and involvement
- dissatisfaction – nay rage – with the status quo
- an inclusive and collaborative approach wherever possible, recognising the sum of the parts is less than the whole
- a flexible and responsive attitude
- integrity, independence and a sense of urgency.

A complete conference report including key recommendations on next steps focusing on advocacy, building community and collaboration can be found in the conference report at www.ncdchild.org

The full conference report can be found at <http://www.ncdchild.org/News/NCD-Child-Conference-Final-Report-Released> ✿



CLAN Commits to EWEC Movement



Ban Ki-moon addresses partners at the EWEC event held at UN Headquarters September 2011 immediately following the UNHLM on NCDs

Launched by UN Secretary-General Ban Ki-moon during the United Nations Millennium Development Goals Summit in September 2010, Every Woman Every Child (EWEC) aims to save the lives of 16 million women and children by 2015. It is an unprecedented global movement that mobilises and intensifies international and national action by governments, multilaterals, the private sector and civil society to address the major health challenges facing women and children around the world.

In September 2011, CLAN was thrilled to attend the EWEC Event at UN Headquarters immediately following the UNHLM on NCDs. This event was a terrific opportunity to celebrate the commitments of so many to the EWEC movement. Indeed, CLAN was proud to have made our own commitment.

Using the September 2011 UN High-Level Meeting (UNHLM) on NCDs as a springboard for future action, CLAN committed not only to our own grassroots efforts to help children who are living with chronic health conditions, but also to the ongoing management of the NCD Child project and advocating for children and adolescents within the global NCD, health and development discourse. More specifically, CLAN committed to efforts aimed at collaboration with a range of stakeholders to run the inaugural NCD Child Conference in March 2012 to maintain momentum around a life-course approach to NCDs following the UNHLM. In our commitment to EWEC, CLAN sought to focus on reviewing the UNHLM Political Declaration and developing a comprehensive policy roadmap capable of guiding future international efforts to redress the many global inequities associated with NCDs and other chronic health conditions that currently impact on the health and wellbeing of children and adolescents. We believe the inaugural NCD Child Conference achieved these aims – and more! ✿

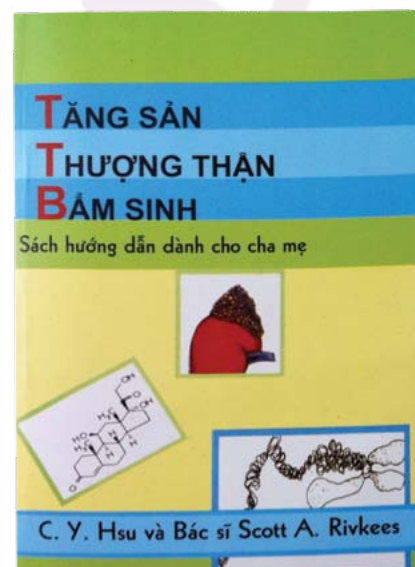
CAH CLAN (CONGENITAL ADRENAL HYPERPLASIA)

The CAH
Community in
Vietnam Grow
Stronger

CLAN was proud to support the Hanoi CAH Club Meeting held at the National Hospital of Pediatrics (NHP) on 9 July 2011, widely accepted by Club Executive and attendees alike as the best CAH Club meeting ever. With 260 families (around half of the entire CAH Community registered with NHP for care) attending, it was clear there had been a strong level of involvement of Club members in organisation, planning and implementation. Volunteers from all provinces stepped forward to help with communication in the future. A new Club Executive was identified to run the Club centrally, with plans for the provincial volunteers to help get messages out to all the members. Given the very large numbers of families, there are now plans underway to start club meetings at provincial locations in the future.

During question time, families communicated that their ongoing main concern remains the price of Florinef. CLAN is grateful to the efforts of the Advisory Commission for Childhood Vaccines (ACCV) as they now directly sponsor some of the poorest CAH families, with plans the new Club set-up will help with the identification of very poor families in future. ACCV is currently sponsoring about 30 children with CAH, 27 with Diabetes and seven with rickets.

Standouts of the 2011 Club Meeting included the launch of Hsu & Rivkees book *CAH: A Parents' Guide*. Now translated into Vietnamese, this comprehensive resource was given free to every family and offers tremendous education opportunities in the future for families and health professionals alike. A presentation by Dr Vu Chi Dung of research conducted over the past two years showing improved outcomes was encouraging for families, and the presence of national Vietnamese media meant the Club meeting aired on Vietnamese National TV with Club President Mr Tran Trung Kien interviewed. Building on the importance of community, the Vietnamese CAH Community's value to all was made clear with a reading of a message of support from CAHSAPI – the Filipino CAH Club – that was translated into Vietnamese language and shared with the Club. Families listened intently, encouraged to know that they are not alone, but part of a larger global community.



CAH: A Parents' Guide

Another highlight of the Club meeting was the attendance by an Australian boy who is living a full and active life with CAH. This healthy young teen was enormously encouraging for all the families and he was likewise hugely impressed by the large numbers of people at the CAH Club meeting and how friendly everyone was towards him.

All in all, the Hanoi CAH Club meeting was an enormous success, and sincere thanks must go to the staff of NHP, Children's Hospital Westmead, ACCV, Clare Parks and others for their fantastic support. The CAH community of Hanoi is making great strides, and it's exciting to see the progress. Meetings with CAH Club Executive and staff after the event confirmed their agreement that this had been the best CAH Club meeting ever, with unprecedented levels of engagement by families. Club Executive members felt encouraged that their workload would lessen now with so many more hands coming forward to help move things forward.

Club meetings at Children's Hospital 1 (CH1) and Children's Hospital 2 (CH2) in July 2011 were also very successful with over 100 families in attendance at the meetings. Like the meeting at NHP in Hanoi, the presentation of information to the families at CH2 by an Australian boy living a full life with CAH was a highlight and a message of hope. Concerns were also raised with respect to the price of Florinef, although inclusions of both hydrocortisone and fludrocortisones in the national insurance scheme is an encouraging step forward. There were many questions for doctors from families about managing CAH and longer term treatment issues. Again, the meetings proved an important avenue for families to learn about the condition and to share their experiences amongst themselves and with health professionals. ✿

Using Multimedia to Educate About CAH

A report by
**Irene Mitchelhill, RN,
RMN, BHSc Nursing,
MN Hons, Clinical
Nurse Consultant,
Sydney Children's
Hospital, Randwick,
NSW Australia**



In 2011-2012, CLAN focused on finding new ways to further address the educational requirements of families and health professionals caring for children who are living with CAH in Vietnam and Indonesia, by developing an educational resource in DVD format. Patient knowledge, understanding and comprehension is essential to achieving positive outcomes and with the increased incidence of CAH in Vietnam and the remote location of many families in rural areas (and across thousands of islands in Indonesia!), improving access to educational resources was considered a priority.

In November 2011, an educational DVD resource developed for families living with CAH in Australia was launched to health professionals attending the Asia Pacific Pediatric Endocrinology Society (APPEs) Conference in Hanoi, Vietnam. With generous funding support from APPEs, CLAN has committed to making this new Psychosocial Education Program (PEP) for Families with CAH available in a range of languages for the Asia Pacific region, starting with Vietnamese and Bahasa Indonesian. Included with the PEP is the CAH Knowledge Assessment Questionnaire (CAHKAQ), which provides a means of evaluation of patient and family knowledge. The resource will also be available for use by medical professionals as they lead staff training.

Translating the resources into different languages is challenging and had to be undertaken with scrupulous attention to detail. The opportunity to translate the verbal transcripts and powerpoint slides for the DVD into other languages came about through the very kind voluntary efforts of four doctors working with CLAN in Vietnam and Indonesia. A Sydney-based health services interpreter narrated the transcript and the DVD was finally edited by a media production company in line with the original filmed speaker presentations. The entire program includes five chapters, which can be individually selected from the main menu: What is CAH; Adolescent and Adult Issues; Psychological Issues; Sick Day Management; and, Emergency Injection of Hydrocortisone. The final DVDs are being printed by CLAN locally in each country, ready for free distribution to all families.

This innovative move to provide education using multimedia methods has the ability to revolutionise the education process. It is cost effective, can be revised by individuals as required, and 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 assistance in seeking sponsorship of the DVD production and duplication, and for enabling me 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. ✨

CLAN Executive Committee Member Profile:

Dr Sue Ditchfield



Dr Sue Ditchfield has been a member of CLAN since 2006. She works as a family physician in Melbourne and is the mother of three children. Her youngest child has a chronic health condition.

Sue was attracted to CLAN because of its human rights perspective and its grass roots approach to the medical, social and psychological problems of children and their families facing chronic health conditions in resource poor countries.

Her own child is able to enjoy a full life, and his condition plays a relatively minor role. If born elsewhere his life journey would have been so different. His growth and development would have been poor, he would have been chronically unwell, or may have died. His family would have faced accessing an unreliable and expensive supply of medications on the black market and very little information about how to manage his condition. The financial and psychological stresses would have been extreme.

Through her work with CLAN, Sue is able to use her medical knowledge and apply her experience to helping families in a very sustainable way. The most positive aspect of CLAN for Sue is the wonderful people she has met and the feeling that it is indeed possible to effect change. ✨

NS CLAN (NEPHROTIC SYNDROME)

What is Nephrotic Syndrome?

Nephrotic Syndrome (NS) is a chronic health condition of childhood in which the kidneys are damaged, causing them to leak large amounts of protein from the blood into the urine. The consequent drop in protein levels in the blood causes generalised swelling of the body, often starting in the face, but then affecting the torso, limbs and other parts of the child's body.

The course and prognosis of NS is notoriously difficult to predict. Unfortunately, for children living with NS in resource-poor countries very little is currently available in the way of access to effective medicine, treatment or support. With strong anecdotal reports that NS is particularly common in Vietnam, a strategic approach to optimising quality of life for affected children must be a public health priority. ✨

NS Club Meetings Start in Vietnam

CH1 Start up their NS Support Club in November 2011

For several years health professionals in Vietnam have asked CLAN to consider starting Clubs to help children with Nephrotic Syndrome (NS) enjoy the highest quality of life possible. The chronic and complex nature of this kidney disease was presenting significant challenges to health professionals and families alike, and high patient numbers and frequent relapses meant the burden on the health system (as well as the children) was enormous. Given the improvements achieved and experienced first hand for children living with CAH and Diabetes in Vietnam, staff were keen to see what more could be achieved for children with NS.

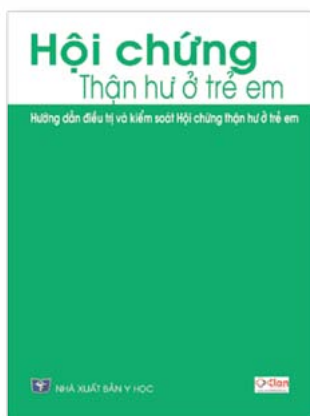
In November 2010 and February 2011 CLAN was proud to collaborate with families and health professionals from the three largest children's hospitals in Vietnam as well as health professionals from Children's Hospital Westmead's Center for Kidney Research in Sydney (Dr Elisabeth Hodson and Dr Allison Tong), to support the launch of inaugural Nephrotic Syndrome Club meetings in Hanoi and Ho Chi Minh City.

The Club meetings themselves were a great success, with over 500 families attending the three meetings. Excellent educational sessions were held, with time allocated for families' questions to the visiting experts at each meeting. A feature of the inaugural meetings were excellent and practical lectures given by hospital staff members on the use of urine dipsticks by families to monitor their child's Nephrotic Syndrome and diagnose relapses early. Families were very keen to be empowered in this way to be actively involved in their child's care.

As usual, much of the success of the meetings was due to preparation ahead of time – most notably with the translation and printing of key educational resources and informational newsletters that were freely given to all families (and health professionals) attending. In addition, Dr Elisabeth Hodson generously prepared excellent medical lectures to share with health professionals invited from distant provinces to learn more about paediatric nephrology, with the objective of strengthening the capacity of the existing health system to effectively and sustainably manage NS moving forward.

Dr Kate Armstrong shared with families the work being undertaken internationally to address chronic health conditions – and in particular, CLAN's efforts within the context of the UN discourse on Non-Communicable Diseases (NCDs) to ensure children are included in all policies and action. The families were encouraged to see themselves as part of the international NS Community, and CLAN was pleased to bring greetings to the CH1 NS Club from the Childhood Kidney Support Network of Queensland, Kidney Kids in New Zealand and NephCure in the United States of America. Families were also asked to complete a confidential and voluntary survey on NS to help all partners learn more about their experiences with NS in Vietnam and the best way for everyone to work together to help effect long-term change that will benefit the children.

One NS Club meeting closed with the speech of a father who shared his feelings about the NS Club meeting and life with NS. He had found the Club meeting very helpful, and thanked everyone for attending. He shared that his own child had been diagnosed with NS two years ago, and it was a time of great shock. In Vietnamese language the words 'Nephrotic Syndrome' translate literally to mean 'Broken Kidneys' and often imply to Vietnamese families that there is no hope at all. Although doctors had explained to him about NS and this had helped him to cope, he has certainly felt very sad and despaired at times, thinking his child would die. Today had offered hope. He closed his talk agreeing with the words of CLAN that “we should never give up” for our children ... agreed! ✨



CLAN Walks Jervis Bay to Raise Funds for CKD Clubs

Many thanks to our CLAN fundraisers who walked 45 km around Jervis Bay on the weekend of 15–16 October 2011 to raise much needed funds for CLAN to establish family support groups for children living with Chronic Kidney Disease (CKD) in Vietnam, and continue to translate medical texts and information books into the different languages of the countries we work.

The weekend was an amazing success, all of our walkers would agree that walking through the mangroves and crossing what could only be described as a small river (not a creek!) on day one and walking the pristine sands of Hyams Beach (one of the best in the world) on the second day were absolute highlights and moments in time never to be forgotten. Again, the entertainment on the Saturday was sensational and what our walkers also come back for each year.

These events would not happen without the commitment and support of some very special friends of CLAN. Especial thanks to Daryl and Mandy Herbert, Chris and Helen Richards, David Hansen, Peter Cole and Tricia McClure for their contribution to the organisation and smooth running of the event and to our very supportive and talented musicians and, this year, our fire dancer, Matt Wall. Thanks must also go to State Custodians Mortgage Company who sponsored the walk. Greatest of thanks to Stephen McClure who, when we thought it was not possible following last year's Six Foot Track trek in the Blue Mountains, planned and executed a very special weekend that raised an incredible A\$33,445.00.

Plans are afoot for our next walk in the coastal mountains of Wollongong in 2012 to help establish a support club for Duchenne Muscular Dystrophy. ✨

Below: Clippings from the Illawarra Mercury's 'Weekender', 28 April 2012



Honorary Associate Member:

Stephen McClure



Since his teenage years, Steve McClure has been committed to helping others through fund raising efforts. Steve is an accomplished musician and keen on maintaining physical fitness and he has used these two pursuits to help him in this endeavour.

Steve met CLAN's Vice President, Cath Cole, through their workplace and after discovering a shared interest in helping others Steve formulated the first plans for helping CLAN raise some much needed funds to continue our grass roots work with chronically ill children in resource poor settings.

Three years later, Steve's commitment has been fundamental to CLAN's continued activities with CAH and Diabetes and foray into new conditions including Nephrotic Syndrome and Osteo Imperfecta (Brittle Bone Disease).

CLAN has recognised Steve's efforts through welcoming him as the inaugural Honorary Associate Member of CLAN. Steve was issued with a certificate of appreciation from CLAN President Dr Kate Armstrong at the fund raising event in 2 June 2012. ✨

DMD CLAN (DUCHENNE MUSCULAR DYSTROPHY)

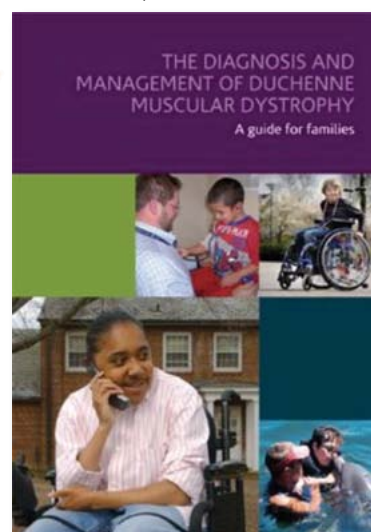
What is DMD?

Duchenne Muscular Dystrophy (DMD) is a genetic condition that mostly affects boys. DMD is caused by a mutation or change in the DNA for a gene (called dystrophin) and results in progressive muscle weakness. DMD is not noticeable at birth, and is most often diagnosed around five years of age when affected boys start to show difficulties standing up, climbing or running.

To date there have been no support groups, educational resources or avenues of assistance for children and families living with DMD in Vietnam. It's time to change that! In May 2013, the Duchenne Muscular Dystrophy Community of Vietnam will come together for the very first time for support, encouragement and education. In collaboration with the National Hospital of Pediatrics (Hanoi), Children's Hospital Westmead (CHW – Sydney Australia), CLAN and members of the international DMD Community, members of the DMD community of Vietnam will come together and help us all learn more about the best ways to help children living with DMD in Vietnam.

One of the key priorities that CLAN will focus on in the first instance will be the development of high quality educational resources on DMD that will benefit the children, parents and health professionals alike. CLAN is grateful to Treat-NMD Neuromuscular Network and Parent Project Muscular Dystrophy for allowing us to translate a booklet, *The Diagnosis and Management of DMD: A guide for families* (pictured right) and a short video on DMD into Vietnamese.

Every child has a right to the most fulfilling life possible, and together we are committed to the brightest future possible for children in Vietnam who are living with DMD. ✨

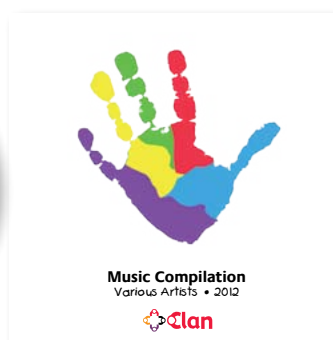


CLAN Records Music Compilation CD

In support of the *Big Night Out*, each of our musicians recorded an original song and CLAN, with the musical direction and technical skill of Steve McClure, pulled together our first CD to help raise awareness and funds. Thanks so much to all of the artists who generously gave of their time and music to make this music compilation a reality. Once again, we can't thank Steve McClure enough for his ideas and drive to make this project happen. ✨

Track list:

- | | |
|---|---|
| 1 Dying To Know – <i>The Penny's</i> | 6 World Is Free – <i>Ranis Fire</i> |
| 2 Take Your Time – <i>Terry Serio's Ministry of Truth</i> | 7 Ordinary Day – <i>My Secret Window</i> |
| 3 Little Feet – <i>Greg Storer</i> | 8 Woe Is Me – <i>Hancock</i> |
| 4 Dilapidated – <i>My Secret Window</i> | 9 Warm Beginnings – <i>Brett Sergeant</i> |
| 5 Jenny – <i>The Maze</i> | 10 Unspoken – <i>Smoke House</i> |



Left: CD. Centre: Front CD insert. Right: Back CD insert.

CLAN's Big Night Out for DMD

A Huge Success

On Saturday, 2 June 2012 over 130 people gathered at the Wollongong City Diggers Club where music, food and fun combined to raise awareness for CLAN and assist our fundraising efforts for future action to help children living with Duchenne Muscular Dystrophy (DMD) in Vietnam. In May 2013 CLAN has committed to hold club meetings in Hanoi for the almost 600 boys attending the National Hospital of Pediatrics in Hanoi for treatment of DMD, and for whom access to educational resources and support is not yet a reality.

Greatest of thanks to our fabulous partner State Custodians Mortgage Company for sponsoring the night, and generously arranging for Nathan Hindmarsh – star performer for Parramatta Eels Rugby League Club – to attend the event. Nathan was a big hit with the crowd and performed silent and live auction duties – as well as judging a fun yo-yo competition for the kids and kids at heart.

Special thanks must also go to Steve McClure for organising outstanding music for the Big Night Out, with no less than eight fantastic bands performing live, including Terry Serio & the Ministry of Truth, Ranis Fire, The Penny's, The Maze, My Secret Window, The Hancock Brothers, Greg Storer & R N R and Smokehouse. Some of these artists – notably Mark Wallis, The Hancock Brothers, My Secret Window and Alex Stengl from Ranis Fire – have been with CLAN on our journey for several years now, promoting our work and helping to raise much needed funds to help children. We are very grateful to you for your ongoing support and generosity with your music and time.

CLAN must also thank the local newspaper – *The Illawarra Mercury* for committing a full page spread to help raise awareness of the Big Night Out and CLAN.

Thank-you so much to everyone involved for a wonderful Big Night Out! ✨



Pictured Top Left: Alex Stengl and Ranis Fire, Top Right: My Secret Window – Brett Sergeant and Steve McClure, Bottom Left: Terry Serio and the Ministry of Truth, Bottom Right: The Pennys



◀ PROTECTING YOUR INTEREST ▶

OI CLAN (OSTEOGENESIS IMPERFECTA)

What is OI?

Osteogenesis Imperfecta (OI) is a genetic disorder of collagen production, and is characterised by bones that fracture very easily. OI is sometimes referred to as 'Brittle Bone Disease'. There are different types of OI, and a person born with OI may experience just a few fractures, or in more severe cases, as many as several hundred fractures over their lifetime.

Research into this chronic health condition means that better treatments are now available, and the use of bisphosphonates is helping to strengthen bones and reduce fractures, bone pain and bony deformities.

Unfortunately, for children living with OI in resource-poor countries very little is currently available in the way of access to effective medicine or treatment. ✿



The Importance of Community

When a child is living with a complex chronic health condition in a low or middle income country, it is very easy for the child and family to be 'lost' within a healthcare system that is not designed to effectively manage chronic health conditions. Affordable access to medicine, quality education and health care, support networks and psychological support are too often not available, and despite their every effort, families fail in their heartfelt desire to ensure their children enjoy the highest quality of life possible. However, when a group of children with the same chronic health condition come together as a 'community', suddenly the impossible seems possible ... and when that community is connected to the broader international community, the impossible can even start to seem relatively easy and achievable.

In a strong show of support a message from Jeneth S Catapang, OI Support Philippines was translated for the OI Support Club meeting offering encouragement in the formation of the community and to achieve the potential of the collective, in particular with respect to advocacy for a better quality of life for the children.

Anecdotally, OI had been causing enormous hardship for the many children affected in Vietnam, and in July 2011 CLAN was invited by the National Hospital of Pediatrics in Hanoi to work with their staff and families to effect change. ✿



Philippines support group

Wishbone Day



Wishbone Day (WBD) is an international community awareness effort for OI, and is officially celebrated on the sixth day of May each year. Individuals, communities and organisations are encouraged to embrace yellow, 'Wishy' and the Wishbone Day phrase to celebrate life with OI.

Special mention was made at the OI Club meeting of Wishbone Day and the day closed with the screening of an inspiring video prepared by WBD set to the tune of *Firework* by Katy Perry. The families watched as dozens of photos of children living with OI around the world and families were able to see they were part of an international community of families living with OI and the vibrant happy photos brought smiles to the crowd of families.

CLAN is grateful to Wishbone Day for translating their video into Vietnamese, and encouraging this new community to get involved in WBD in May 2012! ✿



Inaugural OI Club Meeting, National Hospital of Pediatrics, Hanoi

14 November 2011 saw the first time that families of children living with OI in Vietnam had the opportunity to come together for support and education. Special thanks were given to the families for making the effort to attend with 74 families (from a total of 120 managed for OI at NHP) travelling from all over North Vietnam (some as far as 400 km away), the meeting was an unqualified success.

The OI Club Meeting revealed very clearly that affordable access to Bisphosphonates is the most pressing issue that faces this OI Community, and will offer tremendous opportunities to improve future health outcomes for the children.

Dr Armstrong shared with families how CLAN works at an international level to advocate for better outcomes for children who are living with chronic health conditions in resource poor settings. The inaugural OI Club Community were encouraged that many partners around the world were committed to collaborating with them to help their community to achieve the best outcomes for their children.

There were many visiting dignitaries at the meeting. Sincere thanks to the team of 15 Paediatric Endocrinologists from Indonesia who came along to the OI Club Meeting in Hanoi to learn from their colleagues in Vietnam how Clubs are run elsewhere in the region for children with chronic endocrine conditions. Amongst them the President of APPEs, Dr Aman Pulungan and Dr Kazu Onigata from Japan. Doctors and families in Indonesia have been collaborating with CLAN on Clubs for CAH in the past, and were excited to see how their colleagues in Vietnam do things!

CLAN would like to sincerely thank everyone involved in making the Inaugural OI Club meeting at NHP such an enormous success. In particular, thanks must go to Prof Liem (Director of NHP), Dr Dien (Vice Director of NHP), Dr Vu Chi Dung (Head, Endocrinology Dept of NHP) and his fabulous team, Drs Ngoc, Thao and Khanh) and nurses led by Mrs Hao. Huge thanks must go to Dr Yen-Thanh Mac and Ms Nguyen Van Chi for their invaluable help preparing all of the educational resources shared with families. These resources will continue to change the landscape of OI long into the future, and families were exhorted to read them carefully again and again over the months ahead.

CLAN wishes the OI Club every success for the future and we hope that the inaugural Club meeting in 2011 is just the start of a strong community movement that will result in the children enjoying the happiest and healthiest life possible.✿



The Vietnamese OI Community gathers for their first group photo at the National Hospital of Pediatrics (NHP), Hanoi 14 November 2011



Visiting Paediatric Endocrinologists from Indonesia who attended the OI Club meeting in Hanoi

Translating Resources for the OI Support

With thanks to the Osteogenesis Imperfecta Foundation for allowing CLAN to translate this article and other educational resources (pictured right) into Vietnamese, to share with the OI Community in Hanoi at their inaugural Club meeting.✿



AUTISM CLAN

Building capacity for Autism

CLAN is committed to building the capacity of health professionals working in the field of Autism in Vietnam, and we were proud to sponsor Dr Quynh Trang (a paediatrician from Children's Hospital 1 in HCMC) and Ms Vo Thi Khoai (of Gia Dinh Special School in HCMC) to attend the Asia Pacific Autism Association Conference 2011 (APAC 2011), which was held in Perth from 8–10 September 2011. The APAC 2011 was a seminal event, bringing together experts in the field of Autism from around the region. CLAN was thrilled to co-author a poster that was presented at the conference by Ms Khoai, outlining the fantastic work undertaken at Mai Anh Special School in Da Lat, South Vietnam. ✿



Ms Khoai (right) and her poster about Mai Anh special school in Da Lat Vietnam



Dr Trang presents at the APAC 2011 on challenges caring for children with Autism in Vietnam

MAI ANH – DA LAT SPECIAL SCHOOL

Building Capacity of Parents, Teachers and Carers to Care for Children with Autism at Rural Vietnamese School

Authors: Vo Thi Khoai¹, Valerie Foley², Pham Thanh³, Ha Yen⁴ and Sr Agnes Tuyem⁵ ¹Gia Dinh Special School, Binh Thuan District, Ho Chi Minh City, Vietnam ²CLAN (Caring and Living as Neighbours) ³www.clanchildhealth.org ⁴Children's Hospital 1, HCMC, Vietnam ⁵Mai Anh Special School, Da Lat, Vietnam

BACKGROUND: The Mai Anh Special School in Da Lat (300km from Ho Chi Minh City (HCMC)) in the south of Vietnam is run by nuns in an under-resourced setting. The school provides care for approximately 40 children of local families who are unable to adequately meet the special needs requirements of their children: 28 are hearing impaired (HI); 9 have mental delay; and 10 have Autism Spectrum Disorder (ASD). Despite limited resources, staff (13 teachers: 7 for ASD and 6 for HI) are keen to provide quality care, and in 2008 approached CLAN with a request for training in the field of Autism and HI (see list of concerns in Box 1). After undertaking a capacity building training project for staff working in the field of ASD at Children's Hospital 1 in HCMC in 2010 (with thanks to funding from Hoc Mai Foundation), CLAN was keen to collaborate with partners in HCMC to trial an action research training project in a rural / remote setting to meet the needs of children with Autism there.

AIM/PURPOSE OF PROJECT: The goal of this project was to build capacity of staff, families and volunteers in a rural/remote setting of Vietnam to care for children with Autism and hearing impairment in a community historically, culturally and educationally unfamiliar with ASD.

METHOD: In collaboration with Children's Hospital 1 (CHI) in HCMC and Gia Dinh Special School (also in HCMC), CLAN funded an information and expertise sharing process, with a four-day workshop at Mai Anh School from 20 to 23 January 2011. Initial consultation via email and telephone pre-visit by the HCMC partners helped to establish clear learning objectives and evaluation measures for the project. A budget was determined by Mai Anh School, and the total cost of the project to CLAN was AUD \$800. In January medical professionals from CHI and the Principal of Gia Dinh Special School (see Box 2 on Training provided) then travelled to the Mai Anh School in Da Lat and worked with families, caregivers and teachers to further assess the needs of the children, families and staff, and initiate training.

RESULTS: Medical, developmental and socio-economic assessments of 10 children with ASD (aged between 31 months and 10 years) were completed (see Box 3). Current teaching practices were reviewed and training and recommendations made. Principles of the TEACHH program were shared, and ongoing information sharing processes between the school and the hospital established.

CONCLUSION: At conclusion of training, a formal evaluation was conducted, with ongoing evaluation planned for the 3 and 6-month stages. Key outcomes at the end of the training week (Box 4) as well as evaluation findings at 3-months (Box 5) are shown.

After this initial training, Mai Anh staff will require ongoing support and regular supervision from Children's Hospital No 1 and Gia Dinh school if they are to achieve continued and sustainable change. The staff of Mai Anh have indicated they would like more training on ways to provide psychological support to the educators and caregivers.

Ongoing evolution of this project is planned. However, early results indicate that this project model offers a cost-effective, collaborative approach to building capacity of grassroots organisations to support children and families living with ASD in remote and rural areas of Vietnam.

1 INITIAL REQUEST TO CLAN FROM MAI ANH SPECIAL SCHOOL TEACHING STAFF OUTLINED THE FOLLOWING CONCERNS:

- No knowledge about types of psychological disorders that children have
- Lack of information on characteristics and needs of children with Autism, Intellectual Disabilities or Down syndrome
- Lack of knowledge, experience, method of organising teaching and learning activity for Autistic and Intellectually Disabled children
- Teachers unsure what to do with hyperactive children or children with communication difficulty
- Using kindergarten program for typical children to teach children with special needs, and set teaching goals
- Need to know how to assess and make Individualized Education Programs (IEP)
- Need knowledge on Physical Therapy and Speech Language Therapy.



Dr Thanh, paediatrician, sharing message about diagnosis and treatment of autism with the educators in a special school

2 TRAINING PROVIDED:

- Paediatrician and child psychologist: Dr Pham Ngoc Thanh – Head of Psychology Department of Children's Hospital 1:
 - Held meetings with parents
 - Screened, diagnosed and identified types of Autism
 - Shared knowledge on characteristics and needs of children with different psychological disorders
 - Psychological support for parents and educators.
- Physical Therapist: Ms Ho Thi Kim Yen – Head of Physical Therapy Department of Children's Hospital:
 - Provided knowledge on Speech Language Therapy
 - Provided knowledge on Physical Therapy.
- Special Educator: Ms Vo Thi Khoai – Principal of Gia Dinh Special School:
 - Shared a way of doing PEP 3
 - Made IEP for a child
 - Ways to treat, teach and learn
 - Did Music Therapy and basic Occupational Therapy.



Dr Trang is sharing with parents about caring autistic children

3 INITIAL ASSESSMENT RESULTS:

- Of the 10 children with ASD:**
- Age range was 31 months to 10 years
 - Chronological and developmental age was assessed for each child using PEP-3 (average chronological age was five years and 10 months; average developmental age was one year and eight months)
 - Five children had expressive language.
- Family conditions:**
- Residence distance to the school ranged from 1km to 80km. Number of families living farther than 30km: four
 - Families renting a guest house: 3
 - Children living with the teacher during school days: 1
 - Children living in an unsafe family: 7
 - Employment status of families: administration 7; farmers 5; unstable work 1; no work 3; and commercial work 2.
 - Income range of the families: AU\$150 to AU\$400/month
 - Educational level of the parents: primary 2; secondary 18; and university 5.
- Teachers:**
- Age range of teachers: 27 to 50 years old
 - School teaching time: from 13 months to 4 years
 - Not trained in special education, but participated in some short term training courses: enthusiastic and willing to improve teaching skills
 - Intervention methods used: ABA, floor time, PRT and sensory integration
 - Love children, have patience, and sometimes struggle to control their anger.



Music Therapy with Ms Khoai (front right in black skirt) and educators

4 IMMEDIATE LEARNING OUTCOMES:

- For staff:**
- Understanding of different types of disorders, characteristics and needs of children with disorders, especially Autism
 - Introduction to Speech, Physical and Music Therapy
 - Understand how to assess children with PEP and make IEP according to child's characteristics and needs
 - Staff trained in assessment tools designed to help them identify delays in motor skills, language and social skills
 - Introduction to teaching methods.
- For families:**
- Emotional support – families report feeling confident and accepting of their child's condition
 - Educational support – families report feeling they had more information with regard to autism generally, and strategies to support the development of their own children.



Ms Yen is sharing with parents about speech therapy for autistic children

5 OUTCOMES AT 3 MONTHS:

- Staff integrating programs within the school resulting in the development of self-help, toileting and expressive skills in students.
- Two children since integrated into mainstream school
- Staff report that these children now have expressive language and improved cognitive skills; the children with no language have improved their living skills (such as autonomy in toilet, feeding, clothing activities) and improved communication and social skills.



Maximising quality of life for children living with chronic health conditions in resource-poor countries through:
 1. Access to affordable medication and equipment
 2. Education, research and advocacy
 3. Improving medical management
 4. Encouraging family support groups
 5. Reducing poverty and promoting financial independence
 as the children may grow to enjoy healthy, happy and fulfilling lives and share their experiences with others.

Health Needs Assessment: Autism Spectrum Disorders in Vietnam

A report by
Clare Parks, visiting
intern at CLAN
(abridged)

In mid 2011, Ms Clare Parks, a Psychology student from Notre Dame University (Indiana) came to Australia as an intern with Global Experiences Incorporated (an intern placement organisation based in the USA). An abridged version of Clare's report is below. Many thanks to Clare for conducting this important follow up work, as it provides a solid pathway for improving the lives of children living with Autism Spectrum Disorders (ASD) in Vietnam and other resource poor settings.

In 2010, CLAN, with funding from the Hoc Mai Foundation, sponsored Mr Hoang Quyen, a speech pathologist, Dr Quynh Trang, a paediatrician and clinical psychologist, and Mrs Thanh Tra, a psychologist, from Children's Hospital 1 in Ho Chi Minh City, Vietnam, to visit Australia to expand and develop their capacity in assessment, diagnosis, and management of ASD. All successfully completed a toolkit and developed phased action projects to transfer their learning to their own departments on return to Vietnam.

An exciting transfer of this project was a staff and parent training course held at a remote school for children with Autism in Da Lat (about 300 km from HCMC). The entire project could not have been possible without the generous help of the Hoc Mai Foundation as well as the Australian health professionals, communities, and families that worked together to maximise the benefits of this experience for CH1 staff members during their time in Australia.

Since this project was completed, strong interest has been expressed, by Vietnamese and Australian stakeholders alike, in finding ways to strengthen existing international relationships, and build on early efforts to promote better health outcomes for children living with Autism in Vietnam.

Below (L-R): Clare Parkes,
Dr Kate Armstrong and Nicola Fiddes



A Health Needs Assessment (HNA) was conducted to better understand the status quo for those working in the field of Autism in Vietnam one year after the Autism Project was completed, and explore the support that is potentially available from Australian stakeholders to continue to build capacity in this field. It aimed to review the chief issues that are still relevant to the diagnosis and management of ASDs in Vietnam, and provide interested Australian professionals with the chance to clarify ways they may be willing to support future endeavours – and, more importantly, how their individual efforts fit within the broader picture of improving outcomes for children living with Autism in Vietnam.

In achieving the HNA, in Vietnam, the three health professionals were interviewed as well as a principal of a specialised school, an occupational therapist, three educators and one mother. In Australia, 11 ASD specialists were involved. Two questionnaires were used to address the most current and prominent needs for specialists and health professionals and to assess what resources Australian stakeholders had available and were willing to share.

The HNA process identified that the most desired resources included; volunteers in the areas of speech pathology and training, particularly in diagnostic tools and general volunteers to help in the hospital environment. Other desired resources included courses and information on how to manage ASD, in particular in children over six years of age. Importantly the HNA identified the need for access to other health professionals for development and support in the diagnostic process and to support research projects in Vietnam.



Above: Clare Parkes during her
presentation

Australian stakeholders identified they were willing or able to share knowledge and training (lectures, presentations and workshops – for both parents and health professionals) on subjects such as assessment, diagnosis, therapy techniques, sleep issues, consultation support for schools and general information; early intervention resources and visual language programs; information on working with parents and child care centres staff including materials about challenging behaviours, toileting and toys. ✿

DIABETES CLAN

Diabetes Club Meetings are active and embedded in Vietnam

Three Diabetes Support Club meetings were held for families, one at each of the three children's hospitals. Each meeting had a significant number of attendees, over 350, both returning families and families with newly diagnosed children. Again, like the NS Club, the media were attracted to the conduct of the Support Club meeting at National Hospital of Paediatrics in Hanoi, and their presence provided an excellent opportunity for Dr Dung of NHP to raise

the issue of easier access to insulin - currently, families need to present once a month to their provincial hospital for insulin supplies. Other key issues for families include the importance of psychological support and access to urine ketone strips.



Nicola Fiddes presenting at the July 2011 Diabetes Club Meeting in Vietnam

The Support Clubs create a fantastic opportunity to share and educate. In these meetings esteemed guests including Dr Maria Craig, endocrinologist, Children's Hospital Westmead, discussed complications that can arise from the condition. Dr Thao, at NHP Support Club, presented results of HbA1c / eye complication research undertaken about four years ago and reported a key finding that the higher the HbA1c the increase in risk of cataracts and complications. At five years post-diagnosis 30% of children had eye complications. Similarly, Dr Quynh at the CH2 Support Club meeting gave a very comprehensive and detailed talk to families on Diabetes and it was impressive to see the high level of information that families received. Dr Kate Armstrong brought the international perspective to the Support Club sharing with attendees of NCD global efforts.

CLAN's interns, Clare Parkes and Nicola Fiddes presented with Clare giving engaging families on ways to give psychological support to children living with a chronic health condition and Nicola talked of her own experiences living with Diabetes. So too did three patients present at the NHP meeting (22 year old diagnosed at 11; 13 year old diagnosed at nine; 20 year old diagnosed at 12) who in sharing their stories encouraged families that as you learn more you feel more confident. These young people are living normal healthy lives, studying and working – in this case, earning enough to pay for their own insulin! The presence of these young people who shared their stories was very inspiring for the parents and children – you can grow up to live a happy and healthy life.

Aside from the presentations, the Support Club engages families in many activities that are educational and informative, and for the kids, just a bit of fun. Betacheck test and insulin injection demonstrations were conducted and DVDs – Professor Bumblebee and the DVD created by CHW were played. At the CH2 Support Club meeting, the children learnt how to weave. Learning a new skill is very positive and affirming. Thrilling for CLAN this year was the presentation of awards to students at the Support Club for excellence in their studies!

The Support Clubs are proven strategy for improving the quality of life of the families and children. The doctors report that the families look happier and not as downcast or depressed as in past and the children look healthier. Building on this, at the NHP meeting, it was agreed to launch the Vietnamese Paediatric Endocrinology Group at the Asia Pacific Paediatric Endocrine Society (APPES) meeting in Hanoi in November 2011. This will be a big step forward for Vietnam and a good way to link the growing spread of NCD Support Clubs around Vietnam with tangible support in form of health professional development training.

Sincere thanks to all for organising such wonderful and progressive meetings. ✨

Diabetes: A Journey of Discovery, A Message of Hope

**A Personal Account
by Nicola Fiddes**

(Abridged, see:
www.clanchildhealth.org/index.php/CLAN-Updates/a-personal-reflection-on-diabetes-management-in-vietnam.html)

I came to Sydney from the US for an internship with CLAN. As a psychology student, this placement offered me many great opportunities and related to me on a much more personal level having been diagnosed with Type 1 Diabetes when I was just two years old.

Through my work with CLAN I attended the Diabetes Club Meetings at three hospitals in Vietnam in July of 2011. Coming from the background that I do, full of opportunities and information, I cannot fully describe my shock at the current state of diabetes care in Vietnam. Nothing would have prepared me for the harsh reality check I would receive while attending these meetings.

These annual meetings are the only time families have the opportunity to come together and receive the latest advances in diabetes management and education. Families travel from all over the country, some from over 300 km away from the main hospitals. Dozens of children were lined up waiting to have their height and weight checked, while others were crowded around the HbA1c testing table. Most of the hospitals in Vietnam do not even have their own HbA1c machines. These machines were only here on the day of the meeting thanks to CLAN's efforts and all families were offered free testing. For many of these families, HbA1c testing was not available until CLAN's donations in 2007, and even now most only receive testing once a year.

In contrast, having seen a doctor every three months for 16 years, and then every five to six months for the three years I have been out of pediatric care, that means I have had my HbA1c checked over 50 times in 19 years of living with diabetes.



Nicola Fiddes presenting to a Diabetes Club meeting in Vietnam in July 2011

What struck me even more than the simple lack of HbA1c checks were the levels themselves. With the insulin pump I achieve HbA1c levels of 7.5% or lower. I am still struggling to put into words what I felt when I learned that a handful of these children had HbA1c levels of 14%.

Moreover, the disparities in accessibility of education and support absolutely astounded me. For our trip over to Vietnam from Sydney, members of CLAN packed very lightly so that we could fit hundreds of translated Vietnamese copies of Geoffrey Ambler and Fergus Cameron's *Caring for Diabetes in Children and Adolescents*, a great all-encompassing guidebook on diabetes care. For some of the families, this was the first full version of this book they had received.

In the end, my experiences in Vietnam really boil down to one underlying theme: a complete shock at the difference in standards of care. Whether it is due to the distance between hospitals or lack of supplies, the fact is that these young children living with diabetes simply do not have the same opportunities to live the healthy life I have lived.

I was asked to compose a presentation on my life with diabetes with a message of hope and encouragement. However, the true message of inspiration was that I was standing there, 19 years into the disease having led a happy and healthy life. One mother began crying with joy simply upon being introduced to me. It was one of the most overwhelming experiences of my life – I couldn't believe that my simple existence could ever be enough to elicit such reactions.

I am glad to say that my work with CLAN has both opened my eyes to the troubles facing children with chronic illnesses in countries with limited resources, and also helped show me where my role in helping them is. CLAN's focus is on helping people in countries such as Vietnam to help themselves. CLAN's work follows five main pillars. These pillars, while they will take a certain amount of charitable effort, are aimed at mobilising people to fix the system from within. And so, while my role when meeting the families in Vietnam was to encourage and support, here I work towards educating all of you – on what life with diabetes can be like, what the harsh realities are for these young children, and how you can take action to help our efforts.

No child should be dying from a disease that is manageable. Through the work of groups such as CLAN, the needs of these children and families are slowly being brought to the attention of the international community. In September of 2011 CLAN attends a UN Summit meeting on NCDs, to raise awareness and speak for world's forgotten youth. I truly hope that hearing of my emotional journey through Vietnam can inspire you to help in some way. International awareness may be the first step to finally getting these children the care they need and deserve. ✿

CLAN FINANCIALS

CLAN (Caring & Living As Neighbours) Incorporated

ABN 30 897 322 928

Financial Statements for the Year Ended 30 June 2012

Wishart Powell Pty Limited

1/456 The Esplanade

Warners Bay NSW 2282

Phone: (02) 4948 4766 Fax: (02) 4948 0580

Email: mail@wppartners.com.au

Committee Members

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

Dr Kate Armstrong	Robert Armstrong	Kelly Leight
Heidi Armstrong	Dr Sue Ditchfield	Dr Yen Thanh Mac
Catherine Cole	Amy Eussen	Peter Watt
Valerie Foley	Laura Healy	Dr Andrea Zalan
Dr Boonseng Leelarthapin	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 2012	Year ended Prev Year End
\$6,409	\$18,670

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



Dr Kate Armstrong
Committee Member



Catherine Cole
Committee Member

The accompanying notes form part of these financial statements.

CLAN (Caring & Living As Neighbours) Incorporated

ABN 30 897 322 928

Financial Statements for the Year Ended 30 June 2012

	2012	2011		2012	2011
	(\$)	(\$)		(\$)	(\$)
INCOME			Translation & printing	11,423	2,269
Corporate donations	1,449	-			
Westpac interest	1,104	718	UN Travel	-	194
Other income	-	80	Overseas Medication	2,586	5,140
Donations	-	70,971	Overseas Training	5,124	1,921
Members subscriptions	411	685	Overseas Hospitals	14,343	23,900
Consulting	-	16,155	Overseas Travel/Accommodation	6,623	4,490
NCD Child Projects	70,139	-	Web design	2,236	57
Personal donations	8,075	-	Total expenses	112,386	69,939
Steve Jones FunRaising	4,100	-	Profit from ordinary activities before income tax	6,409	18,670
Walk FundRaiser	33,517	-	Income tax revenue relating to ordinary activities	-	-
Total income	118,795	88,609	Net profit attributable to the association	6,409	18,670
EXPENSES			Total changes in equity of the association	6,409	18,670
Accountancy	1,340	2,000	Opening retained profits	38,849	20,179
ACFID fees	1,702	-	Net profit attributable to the association	6,409	18,670
Bank charges	267	127	Closing retained profits	45,258	38,849
Computer expenses	-	390	CURRENT ASSETS		
Conference fees	1,822	-	Cash assets ⁽²⁾	44,268	38,239
Depreciation	1,318	2,487	Current tax assets	332	(1,366)
General expenses	375	-	Total Current Assets	44,600	36,873
GoFundRaise fees	264	-	NON-CURRENT ASSETS		
Indonesia Training	-	939	Property, plant and equipment ⁽³⁾	658	1,976
Insurance	2,548	-	Total Non-Current Assets	658	1,976
NCD Child Conference	51,022	-	Total Assets	45,258	38,849
Parkistan Training	-	3,830	Net Assets	45,258	38,849
Printing & stationery	8,056	7,198	EQUITY		
RHCI Consultancy	-	2,400	Retained profits	45,258	38,849
Subscriptions	-	312			
TeleConferences	1,336	146			
Travel, accom & conference	-	12,139			

The accompanying notes form part of these financial statements.

Financial Statements for the Year Ended 30 June 2012

Total Members' Funds	45,258	38,849
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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 Tax 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.

CLAN (Caring & Living As Neighbours) Incorporated

ABN 30 897 322 928

Financial Statements for the Year Ended 30 June 2012

Note 2: Cash assets

Bank accounts:

CLAN Inc	1,405	2,616
CLAN Inc Interest	1,020	17,589
CLAN Donations	25,762	156
CLAN Fund	6,276	2,070
CLAN Fund Interest	9,804	15,808
	44,268	38,239

Note 3: Property, Plant and Equipment

Leased plant and equipment:

At cost	4,463	4,463
Less: Accumulated amortisation	(3,805)	(2,487)
	658	1,976
	658	1,976

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.

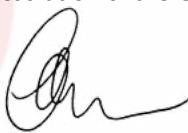
In the opinion of the Committee the Income and Expenditure Statement, Statement of Financial Position, and Notes to the Financial Statements:

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, Deniston 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

The accompanying notes form part of these financial statements.

CLAN (Caring & Living As Neighbours) Incorporated

ABN 30 897 322 928

Financial Statements for the Year Ended 30 June 2012

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 2012.

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.

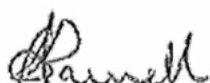
Auditor's Opinion

In our opinion, the financial report presents fairly, in all material respects, the financial position of CLAN (Caring & Living As Neighbours) Incorporated as at 30 June 2012 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 & 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.

Signed on: 20 NOVEMBER 2012



Blair Andrew Powell
Wishart Powell Pty Limited
1/456 The Esplanade
Warners Bay NSW 2282

The accompanying notes form part of these financial statements.
If you have any specific concerns, please contact CLAN at info@clanchildhealth.org

CLAN PARTNERS & SPONSORS

CLAN could not operate without the generous collaborative efforts
and contributions of our wonderful partners and sponsors.

Thank you so much to everyone involved for your care and compassion for children
living with chronic health conditions in resource poor settings.

Change is possible when we all work together!

Alphapharm

<http://www.alphapharm.com.au>

Aspect Australia

<http://www.autismspectrum.org.au>

Atfaal Welfare Society

<http://www.atfaal.com.pk/clan.shtml>

Betachek

<http://www.betachek.com>

CARES Foundation

<http://www.caresfoundation.org>

Children's Hospital 1 (CH1), Hoi Chi Minh City

Children's Hospital 2 (CH2), Hoi Chi Minh City

Children's Hospital Westmead (CHW), Sydney

<http://www.chw.edu.au>

Diabetes NSW, Australia

<http://www.diabetesnsw.com.au>

Grameen Foundation Australia (GFA)

<http://www.grameen.org.au>

Hoc Mai Foundation, Australia

<http://sydney.edu.au/medicine/hocmai/>

Indonesian Pediatric Endocrinology Group

Insulin For Life (IFL)

<http://www.insulinforlife.org>

Life for a Child

<http://www.lifeforachild.org>

Lifestart, Eastwood, NSW

<http://www.lifestart.org.au>

Medtronic Foundation

<http://www.medtronic.com/foundation/>

National Hospital of Pediatrics, Hanoi

http://www.benhviennhitu.org.vn/intro_en.asp

National Institute of Child Health, Karachi

NCD Alliance

<http://www.ncdalliance.org>

Novo Nordisk

<http://www.novonordisk.com.au>

Peekaboo Creations

<http://www.peekaboocreations.com.au>

Philippines General Hospital, Manila

RMIT, Vietnam and Australia

<http://www.rmit.edu.au>

Royal Children's Hospital International (RCHI)

<http://www.rch.org.au/rchi>

Royal Children's Hospital (RCH), Melbourne

<http://www.rch.org.au>

Sozo volunteers

<http://www.sozonet.com/en/sozo-good/sozo-volunteer>

State Custodians Mortgage Company

<http://www.statecustodians.com.au>

Sticky J Jewelry

<http://www.stickyj.com>

Think Walsh Creative Solutions

<http://www.thinkwalsh.com>

Vietnamese-Australian Autism Support Group of Melbourne

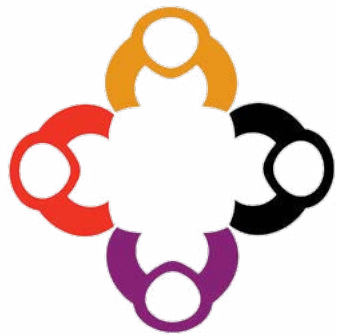
The Vietnamese Parents with Disabled Children Support Group in NSW (Australia)

<http://chamevoiconkhuyettat.org.au/>

Family and friends of CLAN

who support us every step of the way!

www.clanchildhealth.org



clan

Caring & Living As Neighbours



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