

JANUARY 2009 – JUNE 2010



# Clan Annual Report



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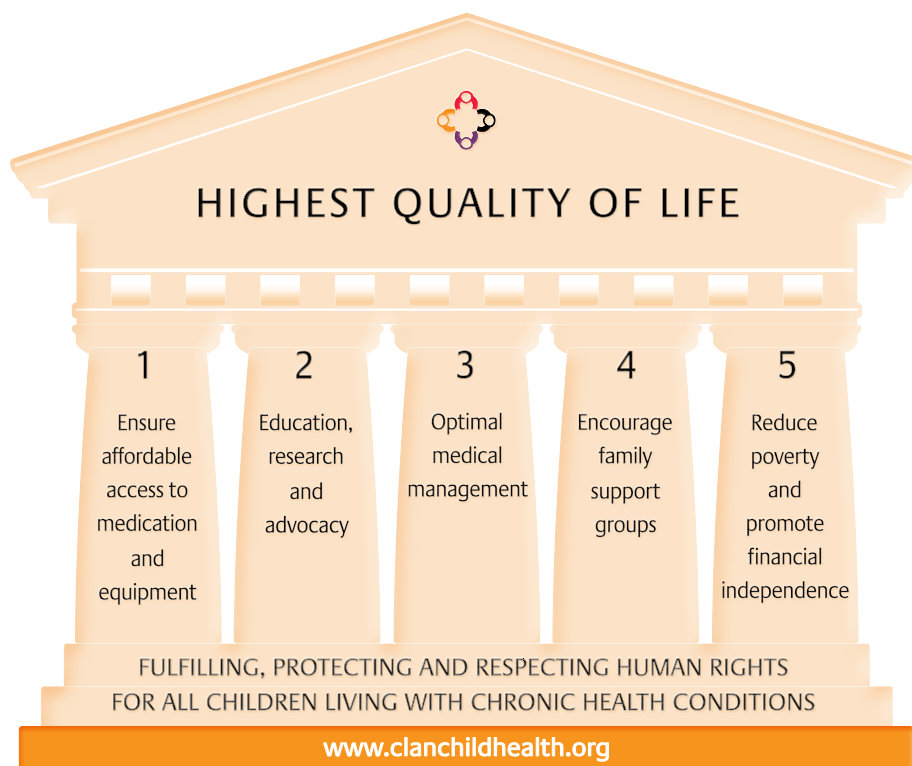
# What is CLAN?

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

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

**Mission** To maximise the quality of life of children (and their families) who are living with chronic health conditions in resource-poor countries of the world.

**5 Pillars** With a rights-based foundation, CLAN's strategic framework for action to maximise quality of life for children with chronic health conditions is based on our 5 Pillars:



# President's Report

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.

## Growth ... by the children, for the children, with the children

There is something special about attending family support group meetings over a period of many years. Not only do you catch up with old and increasingly dear friends; you also marvel at the parade of beautiful children who are literally growing before your eyes. The cheeky toddler who 'strikes a pose' one year becomes the crazy five year old skidding across floors, playing tag with mates, before maturing into the wary seven year old who wouldn't dream of having their photo taken because it's just not cool ...

These are the happy memories. But they are not all happy. The shock of learning the most strikingly beautiful young girl in a Diabetes Club died in her sleep, probably from low blood glucose levels; the passing of a toddler who captured your heart the year before, her own heart giving in to an adrenal crisis; the cruel injustice of seeing young bodies so blatantly ravaged by complications of chronic health conditions simply never seen in high-income countries in 2010.

It is these emotionally challenging experiences that steel CLAN's resolve to change the world for children who are living with chronic health conditions in resource poor countries. Sounds like a big dream, but through partnerships with others we believe it is possible.

The last 18 months has seen remarkable growth for this Australian-based NGO:

- 23 December 2009 — CLAN was granted Tax Deductibility Status in Australia by the Assistant Treasurer, Senator Nick Sherry. In early 2010 CLAN farewelled our 'nest' at Royal Children's Hospital International (RCHI), Melbourne and took our first fledgling leap at independence. Thank you RCHI for your incredible support — you gave us life!
- 18 May 2010 — Give2Asia, a US nonprofit organisation, approved CLAN as a Grantee, thereby enabling a CLAN Fund at Give2Asia to accept tax-deductible donations from US citizens.
- 30 June 2010 — CLAN was formally approved as an NGO for association with the United Nations Department of Public Information (UNDPI).
- June 2010 — saw the launch of CLAN's new website — <http://www.clanchildhealth.org> (with the extremely talented director of *Think Walsh Creative Solutions* winning an award for his amazing work).

There have been other encouraging moments: AsiaLink's Inaugural *Alumni Award* to Cath Cole and myself; and Asia Society's recognition of CLAN as a finalist for their prestigious 2009 *Public Service Award*.

And yet, so much remains to be done. CLAN embraces the challenges before us, as we seek to raise the voices of the world's most vulnerable and disadvantaged children to the ears of the most powerful and advantaged policy makers, movers and shakers. We will use the platforms offered us to advocate for equitable and systems-based change and development that sees the rights of children respected and progressively fulfilled. We will embrace the power of social media networks to Tweet our messages from the highest twee-tops ... and above all, we will maintain our grassroots focus. Communities of children will always be the visual hub that links us with a multisectoral array of stakeholders, focussing our efforts on a common cause: happy and healthy lives for all children, and most especially, for those living with chronic health conditions and disability in resource poor countries.

Please join us. Let's journey with the children and grow together. ✿





# CLAN Office Bearers



## **Acting Vice President – Kelly Leight Esq**

Kelly Leight is the founder and former CEO of CARES Foundation, a US-based organisation that provides support, advocacy and education for those affected by Congenital Adrenal Hyperplasia (CAH), and focuses on research for better care and a cure for CAH.

In June 2009, Kelly attended CAH club meetings in Vietnam and was inspired to become more involved in the work of CLAN to support children living with chronic health conditions in resource-poor countries. ✿



## **Outgoing Vice President – Michelle Konheiser**

Michele Konheiser joined CLAN as Vice President in 2007, assisting the organisation through the process of incorporation. Michelle committed her time to CLAN for humanitarian reasons, having visited Vietnam with her family in 2004, and seeing first-hand the challenges faced by parents whose children have a chronic health condition.

It is with regret that CLAN accepted Michele's resignation in late 2009 (she will be staying on as a general committee member), and we sincerely thank Kelly Leight Esq (founder and former CEO of CARES Foundation) for stepping in as Acting Vice President in 2010.

Thank you, Michele, for your wonderful contribution to CLAN and the children of our region over the last few years. ✿



## **Treasurer – Heidi Armstrong**

Heidi Armstrong is the Treasurer of CLAN and is a qualified legal practitioner. Heidi no longer practices law instead she runs her own 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 is keen to use her skills in running a business to assist CLAN in managing its financial affairs. ✿



## **Secretary – Cath Cole**

Cath Cole is the Secretary for CLAN. She has enjoyed a long career in government and has developed skills in a number of areas including: policy development; project management; program development; development and delivery of education and training; preparation of foundational documents such as strategic and business plans.

Cath first met Dr Kate Armstrong in 2007 where they both participated in the Asialink Leaders Program through Melbourne University. Inspired by the work of CLAN, Cath has been the Secretary for CLAN since it was incorporated as an Independent Association through the NSW Department of Fair Trading, and played a key role in preparing CLAN's application to AusAID for tax deductibility status. ✿

# CLAN Achievements

## Highlights for this reporting period include:

### PILLAR 1

Affordable access to medication and equipment.

- **Congenital Adrenal Hyperplasia (CAH) in Indonesia** – With generous donations from Alphapharm Australia, CLAN has embarked on a collaborative partnership with doctors and families in Indonesia to ensure an uninterrupted supply of medications for all CAH families. This offers families peace of mind, knowing their children are safe, whilst national efforts to secure local supply continue. ✿
- **Florinef in Vietnam** – Through the excellent efforts of the Directorate of the National Hospital of Paediatrics (Hanoi), Florinef has been officially approved by the Ministry of Health for importation into Vietnam. This is great news for children with CAH! ✿
- **CAH in the Philippines** – Health professionals and the CAH community in the Philippines have continued to work hard to secure local access to affordable hydrocortisone and fludrocortisone in their country. Despite inclusion of these drugs in the WHO Essential Medicines List for Children in 2008, these drugs are not yet available in the Philippines. CLAN continues to donate drugs to the local CAH Support Group (CAHSAPI), but this is not a sustainable solution for the longer term. CLAN thanks the local World Health Organisation (WHO) office and health professionals for their actions to effect change. ✿
- A letter from CAHSAPI (CAH Club in the Philippines):

Hello CLAN!

Last November 30, 2009 (Monday) I attended the CAHSAPI 6th General Assembly at Philippine General Hospital (PGH). I've met lot of new members. I shared my stories and hope I touched others' lives.

They've introduced us to the new fellows (Doctors) at PGH Pedia. We also discussed how to get medicines on our own. We know that you cannot donate us every time we need medicines. We are doing everything we can so that we can import medicines but it's hard. Your donation (medicines) were sold at a very minimal amount I think (150–200 pesos per bottle). The money from medicines donation goes to CAHSAPI funds. CAHSAPI and the doctors are talking to a pharmaceutical company here in the Philippines. They can import the medicines but they estimated the price of 1 tablet at 90 pesos. We think that families cannot afford it. You know the life here in the Philippines. We are finding ways to import medicines. We are very thankful that you are here to support us. I know someday CAHSAPI can stand on its own through your guidance.

Thanks! God Bless.

- **Insulin in Vietnam** – In 2008 CLAN collaborated with the International Insulin Foundation (IIF) and International Diabetes Federation (IDF) on a RAPIA (Rapid Assessment Protocol for Insulin Availability) survey for Diabetes, which has since resulted in improved access to affordable insulin in Vietnam. Recognising policy change takes time, CLAN collaborated with Insulin For Life (IFL) and Life For A Child (LFC) to donate emergency supplies of insulin for families at the 2009 Club meetings.
- **Affordable blood glucose monitoring for families in low income settings** — thanks to Betachek Australia for making available their visual monitoring strips. They are cheaper than electronic meters and just as effective. ✿



Families at CAH and Diabetes Club meetings receive supplies of medicine and equipment (L — R: Florinef tablets, Betachek strips and Insulin).



## PILLAR 2

Education (of patients, families, health care professionals, policy makers, national and international communities), Research and Advocacy.

- **Children and families** – In excess of 1,000 families are estimated to have attended all Club meetings supported by CLAN in Vietnam in 2009. Successful Club meetings were conducted for Diabetes, CAH and Autism with interest expressed for expansion of work for children with Chronic Kidney Disease (CKD) in the future.
- **Health professionals** – Thanks to funding from the Hoc Mai Foundation, in late 2009 a nurse from Children's Hospital 1 (CH1) in Ho Chi Minh City was sponsored to spend three months observing best practice at Endocrine and Diabetes Institute of Children's Hospital Westmead (CHW). In early 2009, capacity building for paediatric endocrinology continued with Dr Khanh Nguyen (also from CH1) sponsored by CLAN and Life for a Child (International Diabetes Federation) to spend eight weeks at CHW. During her stay, Dr Nguyen participated in all activities of the Institute and from the wealth of resources that were made available she developed a comprehensive Toolkit to share with her colleagues on return to Vietnam.
- **Policy makers** – Dr Kate Armstrong was accepted to speak at the *International Conference on Realising the Rights to Health and Development for All*, which was held in Hanoi, and was jointly facilitated by the University of NSW, Australia and the Communist Party of Vietnam. CLAN's work informed her presentation, *Grassroots Collaborations as a Means of Realising the Right to Health for Children Living with Chronic Health Conditions In Resource Poor Countries*.
- **Research** – Increasing the capacity of health professionals in resource poor countries to participate in research and publish their findings is a real focus for CLAN. We are extremely grateful to the staff at CHW for their ongoing commitment to a collaborative partnership with colleagues in Vietnam which is already resulting in the publication of Diabetes related research – most notably in the field of Neonatal Diabetes.

Ongoing research conducted by Drs Loan (NHP) and Grover (Royal Childrens Hospital, Melbourne), in the field of CAH during adolescence in Vietnam has likewise resulted in an international conference publication in 2010. Their research findings will contribute to the growing body of knowledge of the difficulties facing children living with CAH in Vietnam.

- **Advocacy** – Dr Kate Armstrong was invited to Kuala Lumpur to participate in the 2009 Asia21 Summit hosted by the Asia Society. This was a unique opportunity to network with key leaders from around the Asia Pacific Region and to advocate for action in the field of child health. CLAN was also a finalist in the 2009 Asia Society Public Service Awards, which were announced at this Summit.

On 30 June 2010, the United Nations' Department of Public Information (UNDPI) Committee on Non-Governmental Organisations formerly approved CLAN (Caring and Living As Neighbours) for association with the Department. This is an important forum for CLAN to raise public awareness about the plight of children living with chronic health conditions. 🌸



CLAN's Strategic Planning Workshop, August 2009.





### PILLAR 3

#### Optimise medical management.

- **All roads lead to Rome** – It has been CLAN's experience over many years that all efforts under the 5 Pillars contribute enormously to strengthening existing health systems and optimising the medical management of chronic health conditions for children in resource-poor settings. For example, enabling a family to affordably access essential medicines; educational resources in their own language; and appropriately trained and qualified health professionals, all greatly impact on child health outcomes.

Of course, there are other specific features of health systems and policies that contribute to positive health outcomes for all people living with chronic disease (such as access to health insurance and subsidisation of medication), which are not yet available in most low to middle income countries. There is an important role for international bodies and policies to start to redress these global inequities and CLAN will use its formal association with the UNDP and other bodies to advocate for change and raise awareness on behalf of the children.

- **Nurse training in Hanoi** – In mid June 2009, a week long nurse training program was conducted in the Endocrinology Department at the National Hospital of Paediatrics, building on the great work of CAH and Diabetes Resource Nurses in this Department.
- **Collaborating with partners in Pakistan** – CLAN is proud to work with Professor Jamal Raza and Dr Yasir Khan at the National Institute of Child Health (NICH) in Karachi, and support their Atfaal Welfare Society (AWS). AWS links with local partners to promote access to essential medication, medical education, affordable quality healthcare, family support groups and broader efforts to reduce financial burdens on families who come to NICH for care. 🌸

### PILLAR 4

#### Encourage Family Support Groups.

- **CAH and Diabetes Clubs in Vietnam** – CLAN facilitated successful CAH and Diabetes Club meetings at the three largest children's hospitals in Vietnam, with inaugural meetings held at Children's Hospital 2 in Ho Chi Minh City. All meetings were greatly appreciated by families and staff alike, and special thanks must go to the staff of CHW who attended and supported these meetings (pictured above).
- **Consumer participation** – CLAN has been contracted by Royal Children's Hospital International (RCHI) and the National Hospital of Pediatrics (NHP) to support the ongoing development of Patient and Family Centered Care (PFCC) in the hospital within the context of family support groups. The program is funded by Atlantic Philanthropies, and is due for completion in July 2011.
- **CAH in Malaysia** – Whilst attending the 2009 Asia21 Summit in Kuala Lumpur, Dr Kate Armstrong took the opportunity to meet with Mr Phil Koh, the inspiring parent of a child with CAH who is working hard with other families and health professionals to progress CAH care in Malaysia.
- **Inaugural Autism Club in Vietnam** – In 2009 CLAN attended the inaugural Autism Club Meeting at Children's Hospital 1 in HCMC. In addition, multiple Autism Support Group Meetings were attended in Hanoi and elsewhere in South Vietnam. Mrs Duyen Lam OAM and Ms Vo Nguyen Tinh Van (pictured right) of the Association for Vietnamese Parents of Children Living With Disabilities in NSW were key speakers at all Autism Club meetings and CLAN sincerely thanks Royal Children's Hospital International (RCHI) for supporting their travel.



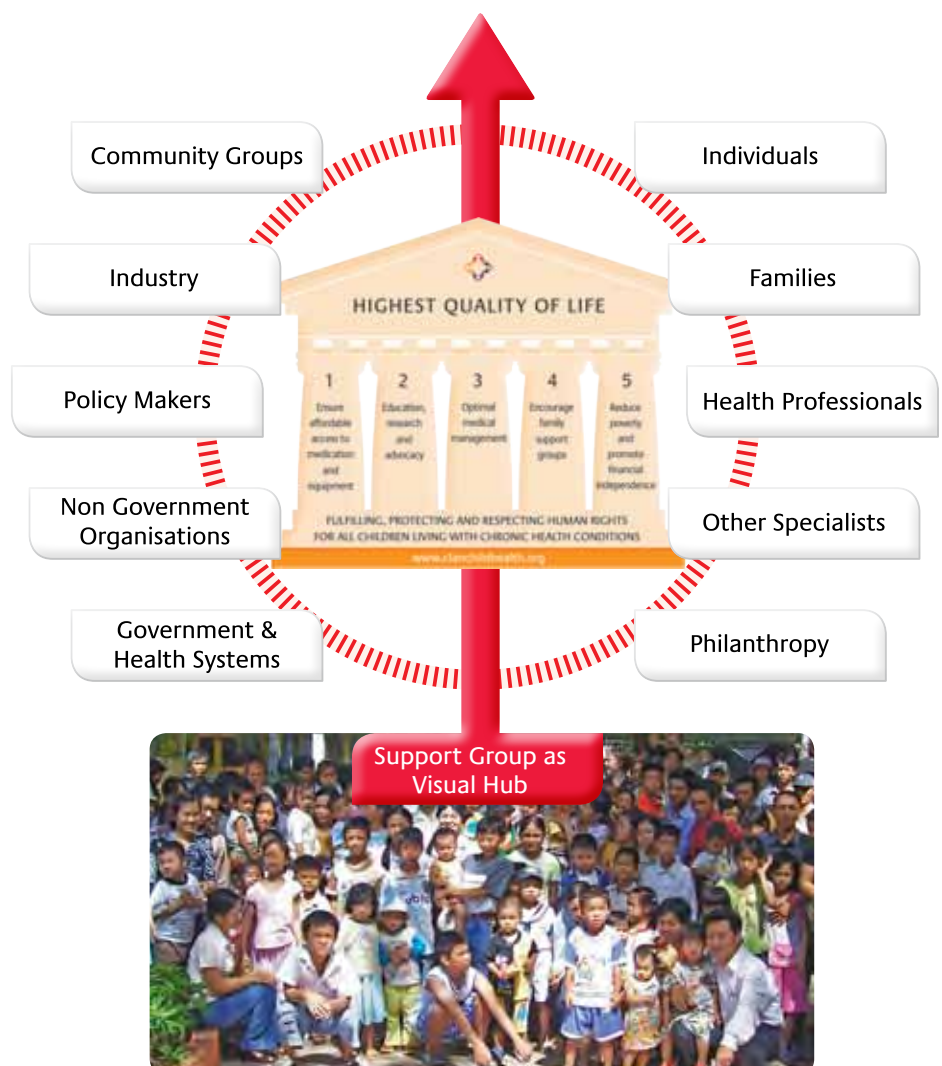




## PILLAR 5

Reducing poverty and promoting financial independence.

- **Working with families to help overcome poverty** – CLAN consulted with families at all Club meetings to discern their views on different options that CLAN might pursue to help families overcome poverty and achieve financial independence. This research will inform CLAN's ongoing efforts in this field.
- **Microfinance in Indonesia** – As reported in 2008, CLAN continues to collaborate with CAH families in Indonesia on our pilot microfinance program. Formal evaluation to date indicates the project has been very successful and CLAN is currently exploring how best to expand this work. We sincerely thank Grameen Foundation Australia (GFA) for their collaborative support.
- **Empowering communities** – Having identified groups of children and families who are living with the same chronic health condition as a distinct community, CLAN focuses on a community development approach to empower such communities to achieve long term sustainable change that addresses local needs and priorities. With communities of children as the visual hub of all action, stakeholder engagement and unity is promoted. CLAN has developed a Community Development Model that encapsulates the key concepts underpinning our work. See the diagram of CLAN's *Community Development Model* below. 🌟



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

# CAH CLAN

## Supporting Congenital Adrenal Hyperplasia (CAH) communities

**Australia STILL NOT screening newborn babies for CAH!**

- As well as helping children living with CAH in resource poor countries, CLAN recognises a responsibility 'to get our own house in order' here in Australia. To this end, CLAN is actively participating in national efforts to raise awareness amongst policy makers in Australia about the grave importance of including Congenital Adrenal Hyperplasia (CAH) within our Newborn Screening (NBS) panel. Australia is increasingly out of pace by not screening for CAH, and CLAN is collaborating with the Australasian Paediatric Endocrinology Group's (APEG) CAH Working Group and CAH Support Group Australia on advocacy efforts, co-authoring a letter on the subject in the Australian Medical Journal of Australia (MJA) in 2010.

**How else can CLAN help children living with CAH in Australia?**

- As an Australian based non government organisation, CLAN is aware that our efforts to help children overseas very often have the potential to positively impact on the lives of children living with the same conditions in Australia. For example, educational resources on CAH, Diabetes and Autism that CLAN has had translated into Vietnamese are already being used by Vietnamese-speaking families here in Australia. CLAN has also had the honour of being interviewed on Vietnamese community radio in Australia, and we hope this is another way of connecting communities in Australia and overseas.

Hi Kate,

Your talk has been broadcast on SBS Radio, Vietnamese program on Tue morning, 15 Sep 09. My husband and I listened to it and we liked it. We found it interesting, especially your view regarding the CAH situation in VN. The reaction from the community was favourable, too. People paid attention to what you said because this is the first time that someone talked about CAH, and not only that, you talked as a parent and as a doctor. That made the content of the broadcast more significant.

Thank you, Kate, we only wish you could have more time and gave more details of your work for the children in VN. Maybe next time!

Kind regards...  
(Name withheld)

**Connecting with CARES Foundation in the USA.**

- In June 2009, founder and former CEO of CARES Foundation, Kelly Leight (pictured below) accompanied CLAN volunteers on a trip to Vietnam. There, she participated in CLAN's support and education programs for families affected by CAH in Hanoi and HCMC. Kelly had this to say about her experience, "I found the people of Vietnam to possess a grace and dignity that infects all of their interactions. I found myself mesmerized by the laughter and play of the children I met. No matter how poorly the children felt and how dire their circumstances, they maintained a cheerful spirit."
- Kelly has observed that the children with CAH living in Vietnam face many challenges such as lack of affordable access to life-preserving medications and medical treatment, lack of parental understanding of the disease and inadequate or non-existent support systems. Parents feel isolated and alone, except when they are together at the CLAN family support meetings. Elation and hope permeated the meeting rooms. Kelly noted that when the families left the meetings, they left with medication, better understanding of the disease, a new group of friends and hope for the future.





**Partnering with Grameen Foundation Australia to expand financial support for CAH families.**

- In the 2008 Annual Report, CLAN indicated that we were embarking on a micro finance project with IKAHAK — a CAH Family Support Group at Dr Soetomo Hospital in Indonesia — and indeed, the first round of loans were issued on 1 February 2009. Families used their access to micro credit loans to establish small businesses such as cafes, a children's library and a sandal making venture.
- Following the successful repayment of the first round of loans in a six to 12 month period, increasingly confident IKAHAK members made an application to CLAN for further first and second round loans — new families were keen to participate and existing families were keen to expand their fledgling businesses. In order to expand, CLAN sought to partner with a giant in the enterprise development field, and was thrilled when Grameen Foundation Australia agreed to partner with us and funded additional loans in April 2010.
- Grameen Foundation Australia brings a wealth of experience to this partnership, and has been a fantastic encouragement to CLAN as we expand this extremely important aspect of our efforts to support the CAH community in Indonesia.
- Special thanks must also go to Dr Amy Prawira (pictured top right) for her ongoing commitment and assistance with translation of formal documentation and communication in relation to this enterprise development project. Amy's help facilitates timely communication with our families in Indonesia and we are very grateful to her for this.
- A letter from CLAN's EDP partners in Indonesia:

Dear CLAN

I'm excited to be able to email you again. The last three months I have been running out of time but very inspired in my work, all thanks to you. Thank God that in the past two months my 'sempoa' (Note: this is a Chinese traditional calculator, that has been used by many tutorial places in Indonesia, in the belief that this helps to improve math skills) course has been very well attended, to the point where I had to decline some students, given the time and place limitations. Even with only 20 students, I feel overwhelmed. Other than that, I have been selling meatballs in the local school canteen... from the sales margins I was able to pay for staff and rental. This is because I also have to look after my children and the course. I (also) design children's T-shirts, which I then pass on to local tailors to be made. This is yet another new business that I am starting. Hence, I have only just found the time to write this email, since I have got into the rhythm of a busy life!

I shall end my email here. I will forward the proposal from another IKAHAK member who would like to join the EDP. Once again thank you so much for your help. It feels like we will never thank you enough for all that you have done for all of us in Indonesia. We wish you and your family every happiness.

Kind regards  
(Name Withheld)



**Thank you Alphapharm.**

- Sincere thanks to Alphapharm Australia for their extremely generous donation of Hydrocortisone tablets (Hysone pictured right) to support the Indonesian CAH community.
- Alphapharm Australia has kindly committed to support a two-year donation program, which allows every child with CAH in the country to enjoy reliable access to this essential medicine, whilst local health professionals collaborate with government agencies to arrange longer term solutions for the country. Regular supplies of medicine mean the CAH community has been able to grow and explore a broader range of options to help the children live happy and healthy lives, and move beyond the fear of worrying about where the next day's medicine would come from. 🌸





# Diabetes CLAN

## A focus on education

**A Nurse Training Project at the National Hospital of Pediatrics (NHP) in Hanoi.**



- Following an AYAD assignment by Claire Henderson in 2008, CLAN was sponsored by Novo Nordisk in 2009 to facilitate a nurse training course at the National Hospital of Pediatrics (NHP) in Hanoi, Vietnam. Nuala Harkin (pictured top left), Diabetes Nurse Practitioner from Children's Hospital Westmead and Karen Jameson (pictured lower left), Senior Diabetes Nurse Educator at Royal North Shore Hospital, were engaged by CLAN for this project work.
- CLAN is grateful to Karen Jameson for agreeing to spend a week in Hanoi, working with nursing colleagues there on an intensive Training Project. Karen has worked in Paediatric Diabetes for 12 years. Her current role is a Paediatric Diabetes Clinical Nurse Consultant based at The Paediatric Diabetes and Endocrinology Unit at the Royal North Shore Hospital in Sydney. Karen is the Convenor for the Paediatric Special Interest Group attached to the Australian Diabetes Educators Association (ADEA) and a member of CLAN.
- Karen Jameson started the project by providing four days of intensive training to the nurses on-site, within the Endocrine ward of NHP. Nuala and Karen then worked in partnership with the nurses at NHP, helping out in the general running of the CAH and Diabetes family support group meetings, which were held on the weekend following the nurse training week.

During her time on the ward, Karen spent a lot of time working alongside the nurses, thereby combining theory and practice during the week. As a general rule, morning sessions consisted of observation and ward-work, and afternoons were set aside for theory and formal practice.

The Nurse Training project was carefully planned to achieve the following key outcomes:

1. A locally developed check-list tool (for Diabetes and CAH) was developed and will be trialed as a means to empowering families in ongoing self-management.
2. A review of sick-day management for CAH and Diabetes indicated good knowledge of these issues amongst nursing staff. Encouragingly, many families interviewed indicated they were confident and happy in their knowledge base.
3. All nurses in the department were aware of the key resources used in the management of Diabetes and CAH in Australia and are keen to implement their use locally — particularly the purple *Diabetes Manual for Parents* and *Professor Bumblebee DVD*, which are both now available in Vietnamese.
4. There is an increasing respect amongst all staff in the department of the importance of education, and the impact it can have on quality of life for the children. 🌸



A nurse training week run by CLAN at the National Hospital of Pediatrics, Hanoi mid 2009.



### Training the Trainers — Van and Khanh.



➤ In mid 2009, Ms Van Nguyen (pictured left), a nurse from Children's Hospital 1 in HCMC Vietnam, enjoyed a crisp Sydney Winter observing best practice in paediatric endocrinology nursing at Children's Hospital Westmead (CHW). Facilitated by CLAN, Van spent 10 weeks in Australia thanks to the generous sponsorship of Hoc Mai Foundation and kind support from staff at the Endocrinology and Diabetes Institute at CHW. Van's placement was greatly aided by six months of complimentary intensive English language lessons she had received thanks to our wonderful partner RMIT (HCMC Campus) prior to coming to Australia.

➤ In order to promote a team-based approach to endocrinology care at Children's Hospital 1 in HCMC, the Endocrinology and Diabetes Institute at CHW generously agreed to CLAN sponsoring Dr Phuong Khanh Nguyen (pictured right) to spend eight weeks in their department in early 2010. A special thanks must go to Assoc Prof Maria Craig for overseeing Dr Khanh's study time in Australia.

➤ Van and Khanh's placement focused on identifying and developing a range of resources that they could share with colleagues and families on their return home. A key priority for Van and Khanh was to increase the number of doctors and nurses in their department who feel confident in the management of endocrine conditions. We are grateful for the support they received from the wonderful staff at CHW, as this ensured their learning objectives and project goals were met. CLAN was also delighted to have Van participate in our strategic planning meeting in August 2009 — we really valued having the voice of such an important stakeholder at the planning table! 🌸



### Educational resources helping everyone learn more about Diabetes.



➤ CLAN's second pillar clearly identifies the need for education at all levels, and we were thrilled in 2009 to launch several new educational resources for use by health professionals, educators and families alike.

Translation of the book *Caring for Children and Adolescents with Diabetes – A Manual for Parents* was a huge success, and printed versions have now been distributed to families, hospitals, universities and at conferences for health professionals in an effort to promote appropriate management of childhood diabetes in Vietnam. Sincere thanks to Novo Nordisk and the authors of the book for this enormous contribution to diabetes care in Vietnam.

➤ Another key resource now available is the delightful Professor Bumblebee DVD in Vietnamese.

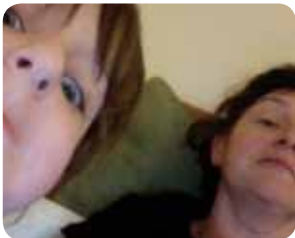
Loved by children and parents alike, this animated character makes Diabetes easy to understand and much less intimidating! Sincere thanks to the wonderful team at Diabetes NSW for making this resource a reality! 🌸



# Autism CLAN

## Supporting communities

### Autism – a new endeavour in 2009.



### Inaugural Autism Club Support Group Meeting in Hanoi.

### Sharing Australian Autism Resources with families in Vietnam.

- CLAN is grateful to Valerie Foley for journeying with us as we embarked on a new endeavour in 2009, to help children who are living with Autism Spectrum Disorders in Vietnam to enjoy a better life. Valerie is a children's television writer and song writer. She has worked on children's programs including Hi-5, Lah Lah's Big Live Band, Magical Tales, The Big Arvo, and In the Box. Valerie is also a trained Early Childhood teacher and the parent of a child with autism.
- Valerie's song, *Through My Eyes*, sung by Thanh Bui opened the Asia Pacific Autism Conference (APAC09) in Sydney and was released in the UK by X-Factor finalist Scott James in early 2010. Valerie is currently working with HIT Entertainment to create Thomas Teaches Special Skills, adapting Thomas and Friends resources to address learning and development in children on the autism spectrum. Valerie works in a voluntary capacity for Aspect (Autism Spectrum Australia) and CLAN, providing services for families living with autism. 🌸
- CLAN's 5 Pillars provided a strong framework for action as we turned our attention to autism, another long-term health condition that affects children. Whilst Autism does not — in the majority of cases — require medication, we found that the overwhelming educational advice families in Vietnam needed to hear, was that there is NO magic cure for autism. Money spent on ineffective therapies is not only money wasted but also potentially dangerous for the children. Modest budgets do not need to be additionally stressed by useless expenditures, so CLAN has sought to reassure families that they do the best by their children to learn as much as they can about autism, speak with other parents, listen to their health professionals and institute simple, inexpensive treatments in the home.
- CLAN's visiting experts from Australia — Mrs Duyen Lam OAM and Ms Vo Nguyen Tinh Van (pictured with flowers with Hanoi Autism Community leaders below) — spent many nights speaking to hundreds of parents of children with Autism, sharing their many experiences and insights with audiences desperate for information they could trust. As Founder and President of the Vietnamese-Australian NSW Support Group for Parents of Children with Disabilities (as well as being the mother of children with Autism and Down Syndrome), Duyen had countless invaluable insights to share with the families.
- In Australia, Duyen and her colleague Van (author of several books on Autism and Disabilities of childhood) work closely with Aspect Australia (a peak Autism body in this country) to help Vietnamese speaking families access a range of useful resources. A huge thank you to Royal Children's Hospital International for financially supporting Duyen and Van to attend Autism club meetings in Vietnam in 2009, where they shared stories, excellent (free) books, websites and other resources (notably a Vietnamese DVD produced by Aspect Australia) with families.

A newsletter from CLAN shared key educational messages, and Dr Kate Armstrong spoke with the families on behalf of CLAN, encouraging them in their efforts to come together as a Club to help one another, secure in the knowledge they are not alone in the world — their neighbours care about their plight and progress. 🌸







### THROUGH MY EYES

Lyrics by Valerie Foley,  
music by Fiona Johnson  
© January 2009.



Thanh Bui

- In 2009, Valerie Foley penned the lyrics to *Through My Eyes* – a song she has written especially to raise awareness of what it is like living with Autism. Valerie has kindly donated 5% of sales to CLAN to continue building on our work to promote awareness of Autism in resource poor countries.

*Through My Eyes* video clip is at: <http://autismfamily.com/through-my-eyes-thanh-bui.html>

- The Hanoi Autism club sang *Through My Eyes* at their inaugural walk through the streets of Hanoi in April 2010 to raise awareness of autism in Vietnam (pictured top middle and right).
- Below are the lyrics to *Through My Eyes* in English and Vietnamese (translated by Le Xuan Truong and Hoang Huy Long).

#### **Through My Eyes** lyrics in English

##### **First Verse**

See the world through my eyes  
it changes shape and it changes size  
it's not quite the world you see  
if you could find a way  
to look around inside my mind  
maybe you would understand me

##### **Chorus**

I'm not blind, but I can't always see  
I'm not deaf, but things can sound strange to me  
I'm not trapped, but it's hard to feel free  
imagine what it's like to be me

##### **Second Verse**

It's hard for me to try  
to think things through or talk like you  
everything can be a blur sometimes  
but if you walk along beside me  
hold my hand and guide me  
together any mountain we can climb

##### **Bridge**

I'm dreaming of my future  
and it's brighter than you know  
I'll get there on a different road  
when I am ready to go

##### **Third Verse**

I don't need pity  
I don't need tears  
I just need someone to help me  
understand my fears  
show me you believe in me  
let me know that I'm OK  
help me feel safe in the world  
and I will find my way.

#### **Through My Eyes** lyrics in Vietnamese

##### **First Verse**

Nhìn ngắm thế gian bằng đôi mắt  
Cuộc đời vạn hình và thế giới vạn màu  
Mà trước mắt tôi chỉ có màn đêm  
Chỉ xin nhìn sâu trong tôi  
Nhìn thấy con tim cũng như mọi người  
Thấy nỗi đau hằn trên cuộc đời này

##### **Chorus**

Nhìn quanh đây bóng đêm bao vây cuộc đời  
Và bên tai những tiếng nghe xa xăm lạ thường  
Đời tôi đây đâu ánh sáng, đâu hy vọng?  
Một ngày như tôi để thấu nỗi buồn này  
Một ngày như tôi để thấu nỗi buồn này

##### **Second Verse**

Rất khó cho người như tôi  
Nhìn cuộc đời bằng đôi mắt bình thường  
Có những khi đời tôi bỗng thấy mập mờ  
Cần một ai đó đến đây cùng bên tôi  
Nắm đôi tay dắt tôi đi  
Thì dẫu núi, dẫu bão táp chập chùng tôi cũng qua

##### **Bridge**

Và trong tim tôi là hy vọng  
ngày mai sống vui như bao người  
Là hiện ngang chân lại bước trên đường  
chờ nắng mang đi màn đêm

##### **Third Verse**

Xin chớ thương hại tôi  
Gạt dòng nước mắt  
Chỉ ước sao người sẽ thấu hiểu những  
Niềm lo âu khuất sâu  
Hãy nói sẽ ở đây bên tôi  
Để tôi biết tôi luôn vững vàng  
Giúp tôi bình yên giữa thế giới  
và đời tôi với những xót xa.

# CLAN Financials

## Income and Expenditure Statement for the Year Ended 30 June 2010

CLAN  
ABN 30 897 322 928

	2010	2009
<b>Income</b>		
Personal Donations	\$7,860.00	\$510.00
Membership Donations	\$681.80	
Corporate Donations	\$5,020.29	
Go Fund Raise	\$2,156.02	
RCHI Final Accounting	\$12,397.45	
RCHI Support	\$3,000.00	
Grameen Foundation Australia	\$2,285.00	
Interest Received	\$178.14	\$0.18
<b>Total Income</b>	<b>\$33,578.70</b>	<b>\$510.18</b>
<b>Expenses</b>		
Accountancy	\$760.00	
Bank Fees and Charges	\$29.93	
Insurance	\$1,388.25	
Legal Fees	\$700.00	
Printing and Stationery	\$866.00	
<b>RCHI Cost Centre</b>		
RCHI - Travel 6 Nights or More	\$3,000.00	
Travel, Accommodation and Conference	\$1,422.90	
CLAN Website	\$1,245.27	
Vietnam – Medication	\$322.19	
Vietnam – Training	\$800.00	
Indonesia – Training	\$1,100.00	
Indonesia – Microfinance Projects	\$2,285.00	
<b>Total Expenses</b>	<b>\$13,919.54</b>	
<b>Profit from ordinary activities before income tax</b>	<b>\$19,659.16</b>	<b>\$510.18</b>
Income tax revenue relating to ordinary activities		
<b>Net Profit attributable to the Association</b>	<b>\$19,659.16</b>	<b>\$510.18</b>
<b>Total changes in equity of the Association</b>	<b>\$19,659.16</b>	<b>\$510.18</b>
Opening retained profits	\$520.19	\$10.01
Net Profit attributable to the Association	\$19,659.16	\$510.18
<b>Closing Retained Profits</b>	<b>\$20,179.35</b>	<b>\$520.19</b>

This financial statement is unaudited. It must be read in conjunction with the complete Accountant's Compilation Report and Notes which form part of the complete financial statements. For further information refer to CLAN Executive.

**Note to financials:** CLAN (Caring & Living as Neighbours) Incorporated was approved by the Australian Treasurer to establish the CLAN Health & Development Relief Fund for Tax Deductibility Status in December 2009. CLAN established an account with Westpac in 2009, and in February 2010 CLAN's account with Royal Children's Hospital International (RCHI) in Melbourne was officially closed, with funds held there transferred to our new independent account.

This financial report does not include "In Kind Donations" that have been made to CLAN. Such donations have been many and varied - from life-saving medication for children, to English lessons for health professionals. We have attempted to acknowledge our partners and sponsors throughout this report, but could never thank everyone enough for their generosity.

# CLAN Partners and 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 low-income 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>

**Complete Party Hire and Shop,  
West Ryde, NSW (for the balloons!)**

<http://www.completeparty.com.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>

**National Hospital of Pediatrics, Hanoi**

[http://www.benhviennhitu.org.vn/intro\\_en.asp](http://www.benhviennhitu.org.vn/intro_en.asp)

**National Institute of Child Health, Karachi**

**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>

**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!



# Donate to **Clan**

Caring & Living As Neighbours



CLAN (Caring & Living As Neighbours) is dedicated to the vision that all children living with chronic medical conditions in resource-poor countries of the world will enjoy a quality of life equivalent to that of their neighbours' children in wealthier countries.

CLAN strives to achieve its mission through a strategic framework for action, focusing on our 5 Pillars:

- 1 - Ensuring affordable access to medication and equipment
- 2 - Education, research and advocacy
- 3 - Optimising medical management
- 4 - Encouraging family support groups
- 5 - Reducing poverty and promoting financial independence.

Taking a rights-based approach, CLAN identifies all children who are living with the same long-term health conditions as members of a united community, and fosters a multisectoral, collaborative approach to community development and sustainable, systemic change. Currently we partner with families and health professionals in Vietnam, Indonesia, the Philippines and Pakistan, supporting Diabetes, Autism, Down Syndrome and Congenital Adrenal Hyperplasia (CAH) communities.

*CLAN is an Australian-based, non-governmental, charitable organisation approved by AusAID for Overseas Aid Gift Deductibility Status and the ATO for Tax Deductibility.*

## MEMBERSHIP APPLICATION

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

I, .....  
(full name of applicant)

of .....  
(address)

.....  
(occupation)

.....  
(e-mail address)

hereby apply to become a member of CLAN. In the event of my admission as a member, I agree to be bound by the rules of the Association in force from time to time.

.....  
SIGNATURE OF APPLICANT DATE

- ☐ CLAN cares for the environment and distributes our Annual Report electronically. Please tick if you require a hard copy.

Please send this completed card with your **\$50** (\$25 joining fee + \$25 annual membership fee) to: CLAN Inc | PO Box 996 | Toronto NSW 2283 | Australia

## MAKE A DONATION

(All donations over \$2 are tax deductible)

- ☐ Yes, I wish to make a regular monthly donation
- ☐ Yes, I wish to make a donation
- ☐ \$25 ☐ \$50 ☐ \$100 ☐ other \$: .....
- ☐ Direct debit – CLAN Inc, Westpac BSB 032-514, Account 196-668
- ☐ PayPal – visit [www.clanchildhealth.org](http://www.clanchildhealth.org) and follow the links to donate
- ☐ Cheque / Money order – please make payable to CLAN Inc\*\*
- ☐ Visa ☐ MasterCard ☐ BankCard
- Card number: .....
- Name on card: ..... \$: .....
- Expiry: ...../...../..... CCV:\* ..... Date: ...../...../.....
- Cardholder's signature: \*\* .....
- ☐ Yes, I would like a receipt – please complete details below:\*\*
- Name: .....
- Address: .....
- ..... State: ..... P/code: .....

\* Credit Card Verification number (3 digits) on the back of your card

\*\* Please send to CLAN Inc | PO Box 996 | Toronto NSW 2283 | Australia

# www.clanchildhealth.org