



## OUR VISION

Maximising quality of life for children and their families who are living with chronic medical conditions in resource-poor countries of the world

# Clan Annual Report 2008

*CLAN (Caring & Living As Neighbours) Incorporated is a not-for-profit,  
Non-Government Organisation, based in Australia*

ABN 30 897 322 928



Evaluating what we do is really important to CLAN.

It is not enough to 'think' that what we do is genuinely helping children who are living with chronic medical conditions in resource-poor countries. This level of evidence is insufficient if we are to convince donors, partners and policy makers of the value of getting involved, and staying involved in the work of CLAN.

So how will we 'know' that CLAN is making a real difference? How can we 'know' if our personal involvement is worthwhile? What level of evidence will we be satisfied with — what will the world be satisfied with? What results will we accept as 'proof' that it is justified to have a go at helping the children in this way?

Interestingly, my role in CLAN is informed as much by what I have learned as a Doctor, working as a clinician and studying and practicing in the field of public health, as it is by my lived experiences as the mother of a child with a chronic health condition.

Living with a chronic health condition day in, day out affords you some very unique insights: the enormously positive impact you can have on your child's life when you are empowered to manage their health effectively; the joy of helping your child to experience their personal life potential to the fullest; the terror of (even imagining) what can go wrong;

respect for the fragility of life, and the vulnerability we all share.

But above all it is the juxtaposition of the positive personal experiences — which have proved to me that life with a chronic health condition need not be all bad — against the heart-breaking stories of families and children who are living with chronic health conditions in resource-poor countries (and who almost exclusively experience the terror and fragility) that convinces me CLAN has a role to play. The global inequity these children endure is not necessary, it is not humane and it is not acceptable.

Through partnerships with amazing individuals, families, communities, health professionals and organisations, CLAN is proving that change is possible. We are all seeing that children living with chronic medical conditions in resource-poor countries can lead fulfilling lives and their parents can have reason to hope for a better future.

The approach of CLAN is novel. There are no other organisations in the world specifically tackling chronic disease of childhood in resource poor countries in the same way. There are currently no international health policies effectively addressing the issue of non-preventable, non-communicable chronic disease of childhood per se, and as a result, the rights of children to health and health care afforded them by the United

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DR KATE ARMSTRONG  
 Founder & President



MICHELE KONHEISER  
 Vice President



CATH COLE  
 Secretary



HEIDI ARMSTRONG  
 Treasurer



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**www.whatisclan.org**



Nations Resolution on the Convention of the Rights of the Child are being systematically ignored.

When we fail to tackle chronic diseases of childhood in resource poor countries we systematically deny millions of children and families every advance of medical science over the past hundred years. At the present time, children in resource poor countries who are living with conditions such as CAH, Diabetes, Asthma, Autism, Epilepsy and other chronic diseases — which in developed countries are routinely synonymous with a high quality of life — are experiencing mortality, morbidity and preventable disability at rates that are not even calculable. Moreover, the voices of these people are effectively lost as families struggle with the day to day burdens of life with chronic disease and the poverty that inevitably follows. Without help it is impossible for these communities of people to advocate for change themselves.

Since 2004, CLAN has demonstrated that very simple, cost effective, sustainable initiatives have the capacity to effect change at community, national and international levels. The potential to do more is limitless, but what will it take to ramp these efforts up? What will it take to translate these early achievements to an international movement that is genuinely committed to tackling the issues relating to chronic medical

conditions in childhood in resource poor countries?

Kenneth Blanchard notes that: *There's a difference between interest and commitment. When you're interested in something, you do it only when it's convenient. When you're committed to something, you accept no excuses; only results.*

When the world becomes committed to helping children who are living with chronic disease, we will see amazing results. As Nelson Mandela has said, "It always seems impossible until it's done".

CLAN is proud to present to you our efforts in 2008. In this annual report we have tried to sincerely thank all those individuals, communities, specialists and organisations who have been a part of the journey — and yet we will have failed to mention even half of all those who have been involved in one way or another.

It is this broad-based, multi-sectoral, collaborative partnership that is the real key to CLAN's success, and on behalf of our neighbours, I would like to express my deepest thanks to everyone who has had the generosity of spirit to move beyond interest to commitment. Together, let's continue to strive for the results we all seek... happy and healthy lives for our children. ✨

**Dr Kate Armstrong**

## THE FIVE PILLARS

CLAN believes the best way to help children living with chronic medical conditions in resource-poor countries is through:

1. Ensuring affordable access to medication
2. Education (of patients, families, health care professionals, policy makers and the international community)
3. Optimisation of medical treatment
4. Encouragement of family Support Groups
5. Reducing the financial burdens that result in poverty.



CLAIRE HENDERSON  
Committee Member



LILEA PROPADALO  
Committee Member



DR SUE DITCHFIELD  
Committee Member



PETER WATT  
Committee Member

# CLAN Highlights

## Presenting CLAN Model to Public Health Professionals in Australia

At the October 2008 State Population Health Conference *Public Health Research for the Real World* held in South Australia, Dr Kate Armstrong delivered an oral presentation titled "A framework for action: helping children who are living with chronic medical conditions in resource-poor countries".

The key aspects of the presentation covered CLAN's five pillars and their theoretical underpinnings; development and implementation of the pillars for children with CAH; perceived benefits and risks; applicability of the CLAN model for helping children with Type 1 Diabetes; and the use of CLAN's pillars as a framework for coordinated, comprehensive and collaborative approaches to other chronic medical conditions of childhood in resource-poor countries.

The presentation highlighted how CLAN enables individuals, community groups, specialists and organisations to implement obligations such as those in articles 6, 23 and 24 of the United Nations' Convention on the Rights of the Child (CRC); article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the Biwako Millennium Framework (BMF) without necessary reliance on state health bureaucracies. CLAN provides a model of community partnership, community development and advocacy.

## CLAN Contributes to Preparation of AusAID Disability Strategy

In August 2008, CLAN was represented by Dr Kate Armstrong at a consultative focus group conducted by AusAID to inform the development of their new Disability Strategy for the Australian government's international aid program. CLAN shared this forum with

representatives from many of Australia's leading disability advocates.

## Networking with Doctors in our Region at APPES Conference

The bi-annual Asia Pacific Paediatric Endocrinology Society (APPES) meeting was held in Seoul in October 2008. Drs Kate Armstrong and Sue Ditchfield attended on behalf of CLAN, with the goal of networking with and learning from the many paediatric endocrinologists that work in our region.



Friends from Vietnam, Pakistan, Indonesia and Australia enjoy some Korean cuisine.

Highlights of the APPES meeting for CLAN included: an oral presentation titled "Understanding the True Burden of Congenital Adrenal Hyperplasia in Vietnam"; a poster display "Survey of a Survivor Cohort: Young people living with Congenital Adrenal hyperplasia in Vietnam"; CLAN's table displaying the five pillars and other facets of CLAN which served as a focus for connecting our work with this international community; hosting a dinner attended by doctors from Indonesia, Vietnam and Pakistan as a means of promoting collegial relations; and a focus group attended by colleagues from resource poor countries from our region to discuss the key issues and challenges they face. Kate and Sue were grateful to the Korean Local Organising Committee for their generous support towards CLAN, enabling us to achieve these goals.

An unexpected highlight of the three-day meeting was presentation of an honorary APPES membership to Kate in

"Recognition of services to APPES and Paediatric Endocrinology in the Asia Pacific Region". Kate is the first person to be made a member of APPES who is not a paediatric endocrinologist.



Prof Chris Cowell presents Dr Kate Armstrong with her APPES Honorary Membership.

## Cycling into CLAN

In March 2008, a friend persuaded me to do a charity cycle trip in Vietnam. I decided I needed to be passionate about my cause because I would be cycling 440km in the mountains of northern Vietnam, with more than 50% being up hill! I decided to raise money for Insulin for Life (IFL). In the process of doing the fund-raising for IFL, Karen Jameson and I had the opportunity to meet Kate, and find out about all the great work that she is doing together with CLAN. We were both inspired by what could be achieved and decided to be a part of Diabetes CLAN. So after the cycle trip, Karen and I met up in Hanoi and visited the National Hospital for Pediatrics (NHP) with Claire Henderson.



Robyn Barnes cycling in North Vietnam.

## Thank you Children's Hospital, Westmead!



Thank you to the staff of the Institute of Diabetes and Endocrinology at the Children's Hospital Westmead (CHW), Sydney Australia, for their commitment to the establishment of collaborative partnerships with colleagues working in the field of paediatric endocrinology in Vietnam.

In 2008 three CHW staff members travelled with CLAN to meet with colleagues at the National Hospital of Pediatrics in Hanoi, and Children's Hospital 1 in HCMC, and provide support at the CAH and Diabetes Club meetings that were held. To this end, special thanks must go to all Department staff at CHW who did not travel to Vietnam, but instead carried the busy workloads of Paediatric Endocrinologist Dr Maria Craig, Diabetes Nurse Practitioner Ms Nuala Harkin and Dietitian Ms Anna Pham (pictured), thereby freeing them to spend time overseas.





We spent a few days with Clare at NHP observing the work she was doing in working towards achieving the five pillars of CLAN. We met nurses and doctors at both NHP and the Adult Endocrinology Hospital of Hanoi. The whole experience provided us with a small snapshot of the plight of children and families living with Type 1 Diabetes in Vietnam. Experiencing

and observing the diabetes services in Hanoi gave us a better understanding of how we can be involved in applying the five pillars of CLAN in working towards short- and long-term solutions for better health care for these children. ✨

**Robyn Barnes**



Karen Jameson in Hanoi.

## Reflections of a Diabetes and Endocrine Project Development Officer in Hanoi

On 10 March 2008, I flew to Vietnam to live and work in Hanoi for six months as an Australian Youth Ambassador for Development (AYAD) as a Diabetes and Endocrine Project Development Officer at the National Hospital of Pediatrics (NHP). This role was made possible by funding from AusAID sought by CLAN to further our work in Pillars Two (Education) and Three (Optimisation of medical management). A significant aspect of my assignment was to develop and facilitate a Train The Trainer program for nurses within the endocrinology department specifically focusing on Diabetes Mellitus and CAH.

Prior to the implementation of the AYAD assignment, families in Vietnam living with Diabetes, or CAH, received very little education to assist with self-management. Education provided to families was generally from doctors who were running extremely busy out-patient clinics, spending only short periods of time in the ward and, therefore, had little time to dedicate to providing education.



Claire Henderson with the team from the Department of Endocrinology, NHP, Hanoi.

Families living with Diabetes, or CAH are often admitted for several weeks at a time when first diagnosed or when readmitted for acute illness. Nurses generally have more contact with patients on the ward and this situation was seen to offer an opportunity for nurses to take on a more substantial role in the education process and empower families to better manage their children's health.



Nursing staff at NHP create educational posters for families.

My previous involvement with NHP through CLAN was advantageous as I knew many of the staff members at NHP and was already familiar with the endocrinology department. As a nurse educator in endocrinology, I considered myself to be in a familiar professional situation to be able to 'hit the ground running' and set up a Train The Trainer program. However, the challenges that arose during the assignment were vastly different from what I had expected: the issues were not so much a lack of knowledge (in fact the nurses

had a really impressive understanding of how to manage CAH and Diabetes) but rather a lack of experience and capacity to influence change within their professional remit. Living in-country provided me with the unique opportunity to analyse, adjust and adapt my own teaching methods to correlate with the way in which local healthcare professionals learnt and worked.

Many changes and achievements occurred during the AYAD assignment, including the development of patient education resources, the development of Diabetes and CAH resource nurse teams who developed and facilitated nurse-led education courses for both CAH and Diabetes and the evaluation of these nurse-led courses presenting good evaluation outcomes. Further, a change in the nurses' perceptions was evident at the end of the assignment. The nurses were more confident in their ability to provide education to families and there was a shift from perceiving education giving as the doctor's role to the nurses perceiving education giving as an important and valuable nursing role. However, most important of all, patient education was perceived by the nurses as a valuable asset for families living with Diabetes or CAH.

Without the enthusiasm, commitment and support shown by the endocrine team, none of the above could have been achieved. Thank you to a great team! ✨

**Claire Henderson**

## Are you looking for a new perspective..?



If you are an Australian health care professional with experience working with children who have chronic medical conditions and are looking to broaden your horizons, contact CLAN to find out more...

Travel, accommodation and stipend will be provided for successful applicants to work in developing countries in your field of expertise in partnership with CLAN and our wonderful partners overseas.

# CAH Highlights

## CAH Drugs on World Health Organisations' Essential Medicines List!

In mid 2008, an application for inclusion of Hydrocortisone and Fludrocortisone tablets within the World Health Organisation's (WHO) Essential Medicines List for Children (EMLC) was jointly submitted by CLAN, Royal Children's Hospital (Melbourne,



World Health Organization

Australia) and the National Institute of Child Health (Karachi, Pakistan). Sincere thanks must go to the huge number of international organisations and individuals who wrote to the WHO in support of this application.

In September 2008, the Second Subcommittee of the WHO "Expert Committee on the Selection and Use of Essential Medicines" met in Geneva and voted to include Hydrocortisone and Fludrocortisone tablets within the EMLC. CLAN is now working with others to translate this great news into a life saving reality for the children of our region.

sharing our analysis of current newborn screening policies (or lack thereof) in this country. We are extremely grateful to the Western Australian Minister for Health who responded swiftly to our request for broader consultation with the relevant stakeholders in his state. We are excited about discussions that are underway regarding screening for CAH in Western Australia in the near future.

We hope to report next year that other states are following this excellent example.

## Families' Sick Day Training in Hanoi

Thanks to the CAH Resource Nurses at the National Hospital of Paediatrics in Hanoi who ran training sessions for families at the CAH Support Club meeting in 2008. Families who successfully completed the training were issued with injection kits donated by CLAN.



CAH families in Hanoi receive their hydrocortisone injection kits.

## New CAH Research Project in Hanoi

A tremendous number of exciting and interesting CAH related projects are happening in Vietnam at the moment. In 2008, CLAN sponsored Dr Sonia Grover, an adolescent gynaecologist from the Royal Children's Hospital (RCH) in Melbourne, to attend this year's CAH Club meeting. Sonia worked with Dr Loan, Claire Henderson (Endocrine Project Development Officer) and Prof Garry Warne (Paediatric Endocrinologist at RCH) to facilitate research in CAH looking at long term surgical, psychological and social outcomes in young women. Dr Sonia Grover and Dr Loan presented

the proposed study to young women and their parents and invited girls over the age of 14 years to participate in the research. This research will assist tremendously in gaining more insight into the difficulties young women face living with CAH and how we can improve services to support young women.

Thank you to Dr Sonia Grover of RCH Melbourne who attended the CAH Club meeting in Hanoi in June 2008 and is continuing to mentor Dr Loan (Adolescent health specialist at NHP) as she researches long term health outcomes for young women living with CAH.

## Learning about Hydrocortisone Injections and Sick Day Care

During the support club meeting, families were given the opportunity to learn how to administer Hydrocortisone. When a child with CAH is sick, it is essential to be able to inject Hydrocortisone to prevent the child becoming seriously unwell. The resource nurses taught the parents how to inject Hydrocortisone safely and those who were competent were given an injection kit and were able to buy the Hydrocortisone from the pharmacy. This education session was just one example of how the resource nurses can help and support families to ensure families feel comfortable with managing their child's CAH at home. 🌸



Dr Sonia Grover (far right) and Claire Henderson (centre) meet with CAH club members from Hanoi.

## Australia Screening Newborns for CAH

CLAN has been working with families and health care professionals in Australia to better understand the barriers to screening all newborn babies for CAH in this country. It can seem ironic at times that our neighbours in some of the poorest countries screen their babies for CAH, while Australia continues to neglect this life saving public health measure.

CLAN has written to all state and territory Ministers for Health in Australia



**Webo**  
<http://www.webo.com.au>

Thank you Webo!

If anyone out there is looking for an organisation to help them to develop a website, go no further than Webo. CLAN is extremely grateful to the staff at Webo who listened to what we needed in a website, worked with us to develop ideas, and then helped us transform dreams into reality.

Thank you to Webo for making all their services available to CLAN at prices we could afford. Webo continue to give us excellent after sales support, making our new website both easy to use and maintain.



## Did you know ...

Congenital Adrenal Hyperlasia (CAH) is the most common adrenal disease of childhood.

With daily replacement of Hydrocortisone and Fludrocortisone

tablets, children with CAH should expect to enjoy long and healthy lives.

In resource poor countries, such tablets are not affordably available.

Families struggle to buy these essential drugs on the black market. Most children die, or suffer the terrible side-effects of poorly controlled CAH.

## Update From Pakistan

National Institute of Child Health, Karachi, is a tertiary health care teaching hospital under the umbrella of Ministry of Health. The 475-bedded facility caters to extremely poor patients from southern Punjab, Baluchistan and from all over Sind (approximately 3.5 million children). Since 1999, we have been running an Endocrine OPD under the supervision of Prof Syed Jamal Raza, with over 200 Congenital Adrenal Hyperplasia and over 500 Diabetic patients registered with us.

In October 2007, Prof Syed Jamal Raza had the chance to meet with Dr Kate Armstrong and Michele Konheiser in Ho Chi Minh City. The meeting was successful and since then, the Atfaal Welfare Society (AWS), with the support of CLAN, has been able to revolutionise the quality of treatment provided to our patients.

### 24/7 Emergency Support

The first step taken by CLAN and AWS was the hiring of a doctor to educate the CAH families. Through this program the patients are now able to contact the educator 24/7 and discuss all types of issues like nearest medication availability and general medical information. The educator is also available to talk to their family physicians in case of an emergency and advise appropriate measures needed for the patients.

### Availability of Medicine

This is a major concern for patients and their families in Pakistan. Unfortunately, medicines are only available at selected major pharmacies in Karachi and Lahore.

CLAN and AWS together have now made available these medicines through various sources. Patients are now able to get Hydrocortisone tablets made to their specifications, making possible exact required dosage.

### Counselling of Families

Most patients and their families are in denial over the fact that a family member has been diagnosed with CAH. The main reason being their lack of understanding of this disease. Now with the help of the educator, parents are able to hold one-on-one sessions in total confidentiality and are able to learn about their child's illness in detail.

### CAH Club

The initial stages of forming a CAH Club have been effectively completed. All CAH patients have been registered and a database established so all contact details and important information is stored in one place. This has helped us understand CAH in Pakistan and move forward in achieving our goal of forming a successful CAH Club.

### Printing of Materials in Native Tongue

CLAN has financed the translation of the CAH handbook for parents into our native language for the convenience of our patients. This translated book is in the process of being distributed to doctors all over Pakistan with registered CAH patients. The book has helped families with CAH patients to better understand the disease and medication. A separate section has been included for the families on how to give medication according to various age groups.

With the support of CLAN, we have been able to design our own Diabetic



Prof Garry Warne's book, "Your Child with Congenital Adrenal Hyperplasia" translated into Urdu (Pakistan).

educational materials. AWS now has a variety of materials in both English and Urdu from dietary advice to Diabetic emergencies and complications.

### Investigation

In the past, 17OHP was only available in one private hospital, therefore, this investigation was out of reach for most families NICH catered to. Now AWS has been able to start this investigation on a cost-to-cost basis. Some investigations are done free of charge for the extremely non affording patients.

### General Awareness Programs

General awareness programs catering to general physicians, paediatricians and general public have been held for Diabetes, CAH and other endocrine disorders.

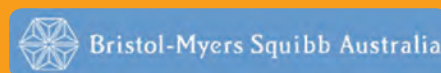
### Other Endocrine Diseases

CLAN has been a huge inspiration for us. We have started through various partnerships to arrange facilities for patients suffering from other illnesses like Turner Syndrome, PWS etc. ✿

Dr Yasir Khan

## Sincere Thanks to our Humanitarian Partners!

The humanitarian support that CLAN has received from Alphapharm and BMS has had a profound impact on the lives of all children living with CAH in our region. Emergency donations of life-saving drugs meant that children did not suffer, while broader efforts were made to include Hydrocortisone and Fludrocortisone tablets within the World Health Organisation (WHO) Essential Medicines List For Children.



# Diabetes Highlights

## RAPIA to Help with Insulin Access

After attending our first Diabetes Club meeting at the National Hospital of Pediatrics in Hanoi in 2007, CLAN soon realised that access to affordable Insulin was a major problem facing children living with Diabetes in Vietnam. As per CLAN's framework for action, our first pillar clearly identified that this issue had to be addressed as a matter of urgency.

Sincere thanks to David Beran and the rest of the team at the International Insulin Foundation (IIF) who collaborated with the International Diabetes Federation (IDF) and Vietnamese colleagues in 2008 to commence work on a Rapid Assessment Protocol for Insulin Availability (RAPIA) survey in Vietnam.

The extensive consultation that forms the RAPIA process (with interviews of key stakeholders at the macro, meso and micro levels) will provide clear insights into the challenges facing all people living with Diabetes in Vietnam. CLAN is particularly optimistic about the outcomes this great work by the IIF, IDF and Vietnamese colleagues may have on health outcomes for children who are living with Diabetes in Vietnam.

Given Congenital Adrenal Hyperplasia (CAH) is a less well known medical condition than Diabetes, CLAN was particularly keen to utilise this opportunity of working with the IIF to simultaneously conduct a CAH RAPIA Survey in Vietnam. We expect to have a formal report available in



Small group discussions at the Hanoi Club meeting, held at a local water park.

2009 and will seek to disseminate the findings of the CAH RAPIA as broadly as possible. Moreover, CLAN also plans to incorporate key learning and insights from both RAPIAs into our organisational strategic planning processes to optimise our efforts in helping children with CAH and Diabetes in Vietnam enjoy the highest quality of life possible.

## Partnering for Humanitarian Aid

CLAN continued to grow our relationship with Life for a Child (LFC) and Insulin for Life (IFL) with more donations of Insulin made to children in Vietnam. CLAN is optimistic that the recent findings of the RAPIA survey will help all stakeholders to determine the most strategic way forward to help the children.



Families receive free Insulin from Insulin For Life.

## First Diabetes Club Meeting in South Vietnam

In July 2008, the inaugural Diabetes Support Group meeting was held in Children's Hospital 1 in Ho Chi Minh City. Many thanks again to AusCHAM for their generous contribution and our colleagues at CH1 and Children's Hospital Westmead for all of their hard work and making this meeting such a success. A key outcome of this meeting was an opportunity for families to share (often for the first time), the difficulties and challenges they face living with Diabetes.

CLAN was particularly impressed by the professionalism and compassion shown



Prof Maria Craig shares information with families at the Inaugural Diabetes Club Meeting in Ho Chi Minh City.

by the Psychology Department of CH1 in their conduct of focus groups for families at the meeting (see report on opposite page for outcomes). CLAN was, therefore, only too happy to agree to requests from the Psychology department to collaborate with them in 2009 for the establishment of an Autism Club in Ho Chi Minh City; again, the first of its kind in South Vietnam.

## People UNite in London for Diabetes

On 25 October 2008, the IDF convened a meeting on "Access to Essential Diabetes Medicines for Children in the Developing World", bringing together key individuals and organisations from around the world to discuss the humanitarian emergency facing children living with Diabetes in resource poor countries. CLAN was honoured to be invited to participate in this meeting and, in particular, appreciated the chance to partake in the focus group meeting on education related issues.

Since the United Nations' resolution in 2006 declaring 14 November "World Diabetes Day", the plight of children living with Type 1 Diabetes in resource-poor countries is receiving increased attention, and it was encouraging to see representatives of the World Health Organisation, Ministries of Health, the pharmaceutical industry, NGOs and others, brought together at a single forum to discuss solutions for change.

[www.stickyj.com](http://www.stickyj.com)

**StickyJ**® Jewelry

Sticky Jewelry (an American company), has generously donated free medical identification bracelets to CLAN for use by children with diabetes and CAH. The bracelets are brightly coloured, cheerful and highly sought after by families! Because it is common practice in Australia and other developed countries for all children with CAH and Diabetes to wear medical bracelets, CLAN believes that all children should be offered the same opportunity, and we thank Sticky J for making this possible.





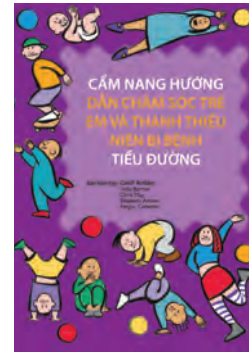
## Educational Resources on Diabetes

Thanks to AusCHAM and other donors, CLAN was able to engage the services of our fantastic film makers (Johnny Tran and Joanne Saad) to create a DVD aimed at families, sharing tips for a happy and healthy life with Diabetes.

The DVD was made possible by the contribution of staff at CHW and the involvement of two extremely generous Australian families who

shared their time and stories for the benefit of the children in Vietnam.

With the translation of the Purple Diabetes Manual for Parents almost completed, it was possible to share excerpts in a CLAN newsletter that was printed and distributed free of charge to families. We sincerely thank Novo Nordisk and the editors of this Manual for helping to make this resource available to Vietnamese speaking families around the world. ✨



Caring for Diabetes in Children and Adolescents - A Parents' Manual — now available in Vietnamese.

## Results of the Diabetes Club Small Focus Groups at Children's Hospital 1 (CH1)

At the inaugural Diabetes Club meeting at CH1 in Ho Chi Minh City (HCMC) on 3 July 2008, members of the Psychology Department divided the attending 40 families into small focus groups, and facilitated discussions; helping families to connect with one another and share the main issues they face in their everyday lives with Diabetes.

For the majority of people, these discussion groups represented the very first opportunity most families living with Diabetes in South Vietnam had had to speak with other people about their experiences living with Diabetes. For some it was a very emotional experience, but from the feedback given to us by families, it was clear that overall all participants found it to be a very helpful and satisfying process.

The small groups were provided with some questions to prompt discussions. Responses were then transcribed and reported back to all families at the end of

the day. We share with you now some of the key findings:

### What do parents know and understand about their child's Diabetes?

- Feel they have no information on Diabetes, and have had wrong knowledge from the beginning
- Sources of information include relatives, neighbours and friends. Some buy books, and although they can read the information and understand it, putting the information into practice is difficult
- Few parents ask doctors about Diabetes.

### How did parents feel when initially told about the Diabetes diagnosis?

- Worried about the present and future.
- Surprised and shocked
- Sad because of incurability and they feel this is such a severe disease
- Confused because of lack of

- information and support
- Fearful, hurt and in pain.

### What are the main difficulties facing families living with Diabetes?

- Financial burdens are enormous; it is hard to access the drugs needed. There is a feeling of hopelessness with the need for long-term treatment. Families who live far from HCMC face additional burdens (long journeys to HCMC, lack of time, expenses of transportation, drain on the child)
- Children have fears of blood tests; parents feel their children's pain, but try and appear happy to support their child
- Parents unsure how to support their children emotionally
- Parents feel overwhelmed, overloaded, empty, lost and in need of support
- Many difficulties relating to school:
  - problems concentrating
  - visual difficulties for the children
  - child often too tired, and being left behind his/her classmates
  - child feels different from peers
  - parents feel sad about difficulties their children having at school.

### Who can parents share feelings with?

- Many families share their emotions with their partner, siblings, extended family and teachers
- Some parents have no one
- Many find it hard to share
- Parents would like support from psychologists to help work through their emotions. ✨

Dr Quynh Trang



## Betachek Visual Monitoring Strips



are an exciting alternative to battery driven, expensive blood glucose monitors.

Thanks to Betachek for allowing CLAN to access these strips at reduced prices and increase the affordability (and, therefore, likelihood) of blood glucose monitoring for children living in Vietnam.



Many thanks to Hot Air Conferencing, who generously offered CLAN discount rates. With committee meeting members scattered around the world, this makes a huge difference to our ability to communicate effectively and affordably.

## AusCHAM Grant

We have great pleasure to advise of the successful outcomes relating to the use of the Charitable Program funding received by CLAN from AusCHAM in 2008.



Funds from AusCHAM, in combination with funding provided by CLAN contributed to:

- The commencement of a Diabetes Club at Children's Hospital 1 (CH1) — the first of its kind in South Vietnam
- Ongoing development work with the CAH Club at CH1 — a Club founded with CLAN's support in 2005
- Facilitation of drug donations to CAH and Diabetes Clubs
- Creation of a Diabetes educational DVD for use by families and children

- Translation of educational resources including the Purple Diabetes Manual for Parents
- Transport and accommodation costs for three members of Children's Hospital Westmead, Diabetes and Endocrinology Department staff to attend meetings in Vietnam and meet colleagues with views to establishing a long term collaborative partnership
- Purchase of medical equipment for humanitarian aid
- Vouchers for the poor to cover travel and medical costs
- Translation of CLAN newsletters for CAH and Diabetes Support Club members
- Logistics and administration costs in relation to the conduct of the Support Groups and Focus Group
- Provision of food for families at all meetings
- Provision of playgroup and volunteer facilitators with games and toys for children at Club meetings

- Enterprise development projects established for CAH Support Club.

CLAN is able to report that on 2 July 2008, the third annual CAH Support Club meeting was held at CH1 and attended by 75% of all CAH families who attend CH1 for care.

On 3 July 2008, the inaugural Diabetes Support Club meeting was held at CH1 and was attended by 90% of families receiving care for Diabetes at CH1.

Feedback from families and staff of CH1, together with CLAN's observations based on many years' experience, indicated that the meetings were highly successful.

**CLAN is extremely grateful for the support received from AusCHAM in 2008. Without AusCHAM's financial assistance our vision for the children of CH1 would not have borne such substantial fruit.** ✨

## IKAHAK: Trialling Microfinance in Indonesia

As per our fifth pillar, CLAN firmly believes helping families achieve financial independence is the key to them accessing long-term, sustainable, quality health care for children who are living with chronic medical conditions.

Because CAH is a relatively uncommon medical condition, it would be rare for CAH families to meet one another in traditional community settings. Rather, CAH families in resource-poor countries are usually introduced to one another by medical professionals, and come together as a community for the first time by virtue of their attendance at a tertiary medical centre for health care.

As a result of the non-geographically based nature of these communities, traditional approaches to micro-finance and enterprise development are not helpful. For example, sinking a well will not help the CAH community in any country to achieve better health outcomes. New ways need to be considered...

In 2008 — after a direct request from the CAH Community in Indonesia to help them in this way — CLAN consulted widely with experts in the field to prepare a comprehensive and ethically sound model that could be used to trial microfinance amongst CAH Club members in Indonesia. Close consultation with Indonesian cultural brokers and CAH community members was vital to ensuring culturally safe and appropriate approaches were adopted.

Accurate translation of information in the development phase was essential to ensure all community members contributed equally.



Sincere thanks must especially go to new CLAN member and vital cultural broker Dr Amy Prawira (pictured below) for her help at all stages of the process!!



IKAHAK — CAH Club in Surabaya.

CLAN will be trialling this model in 2009 with the overriding principle of 'above all do no harm'. Encouraging the CAH Club members to work as a united community, CLAN emphasises the fact that it will not be possible for families to 'fail', but rather any and all outcomes of the project will contribute to our collective understanding of this novel approach to helping children and families who struggle to achieve happy and healthy lives with chronic medical conditions. ✨

*Any donation to CLAN will be joyfully accepted!*

### Please contact:



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Thank you to RCHI for managing CLAN's finances for the last four years. Without your help, we wouldn't be where we are today.



# Financials

## CLAN STATEMENT OF FINANCIAL PERFORMANCE

### 1. REVENUES:

Balance Brought Forward (2007) .....	\$22,914.79
Monies Received as Donations.....	\$21,899.07
Interest Received as Interest.....	\$997.74
Novo Nordisk Sponsorship.....	\$7,613.00
<b>Total Revenues .....</b>	<b>\$53,424.60</b>

### EXPENSES CONTINUED:

Consultancy and Media Materials.....	\$9,326.04
External Catering Vietnam .....	\$547.00
Scholarships.....	\$1,329.67
Overseas Travel for Sponsored Experts.....	\$8,728.67
RCHI Facility Fee .....	\$375.00
<b>Total Expenses .....</b>	<b>\$21,985.38</b>

### 2. EXPENSES:

Administration.....	\$1,679.00
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3. **BALANCE AT END OF YEAR.....** \$31,439.22

## CLAN STATEMENT OF 'IN-KIND' PROVISION OF SERVICES

Provider	Expense Category	Estimated Value	Comments
Individuals	Courier expenses	\$2,524.55	Sending medical supplies overseas and general postage
Individuals	Incorporation Expenses	\$2,316.75	Expenses incurred in moving to Incorporate CLAN
Individuals	Educational Resources	\$2,796.00	Printed materials, DVD's, other learning resources
Various	Materials purchases — medications	\$9,454.01	Alphapharm, Bristol-Myers Squibb, Pfizer
Various	Materials purchases — medical supplies	\$2,486.00	Insulin for Life, Betachek
Sticky J	Medical ID Bracelets	\$900.00	CAH and Diabetes Medic Alert Bracelets
Individuals	Sponsorship of overseas meetings and events	\$2,276.11	Meetings, catering expenses and small gifts for children attending
Individuals	Printing and Stationery	\$130.97	
Individuals	Professional Consultancy	\$2,595.00	Graphic design; PEEKABOO Creations, Mal Salmon
Individuals	Establish Office	\$2,450.00	Expenses incurred in setting up office
Various	Travel	\$5,227.18	Overseas Travel and Accommodation
	<b>TOTAL</b>	<b>\$33,156.57</b>	

Note: Volunteers have contributed hundreds of hours of support of CLAN.

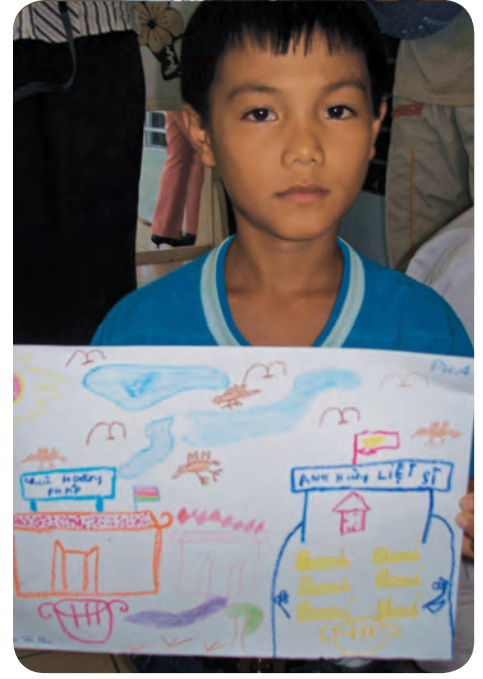


Thanks to generous funding from AusCHAM, CLAN is working with the CAH Club in Ho Chi Minh City on a number of projects dedicated to helping families escape the financial pressures of living with CAH. CLAN is helping families establish small income generating businesses as well as trialing 'Your Colours' — a project run in the busy outpatient departments that allows families to exchange small drawings for much needed cash, thereby helping them cover immediate health care costs.

*"Overcoming poverty is not a gesture of charity. It is an act of justice"* NELSON MANDELA



# Helping children and their communities to grow



*"Science and art belong to the whole world, and before them vanish the barriers of nationality."*

Goethe



Thank you for your generous support during 2008

[www.whatisclan.org](http://www.whatisclan.org)

## Would you like to get involved?

Please email us at [getinvolved@whatisclan.org](mailto:getinvolved@whatisclan.org)