



## 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

Year Ending 31 December 2007

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

ABN 30 897 322 928

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DR KATE ARMSTRONG  
Founder & President



MICHELE KONHEISER  
Vice President



CATH COLE  
Secretary



HEIDI ARMSTRONG  
Treasurer



DR SUE DITCHFIELD  
Committee Member

# PRESIDENT'S REPORT

Dr Kate Armstrong

## THE WHEEL'S IN MOTION

In 2004 reports in Australian and American CAH (Congenital Adrenal Hyperplasia) Support Group newsletters outlined the desperate plight of children living with CAH in North Vietnam. Families were bankrupting themselves trying to afford the medication required by their children on a daily basis just to survive, and the resultant rationing of doses led to morbidity and mortality on a devastating scale. The inequity between life for children living with CAH in Australia and Vietnam was striking.

CLAN (CAH Living As Neighbours) was founded in 2004 in response to this inequity. After receiving generous support from Alphapharm and Bristol-Myers Squibb to provide humanitarian donations of medication for the children (Hysone and Florinef tablets respectively), it became rapidly apparent that huge changes could be achieved for CAH families in Vietnam with relatively simple, cost-effective initiatives.

## 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.



CLAN identified our five pillars on which to base all activities, and in collaboration with other interested parties early activity in Vietnam included: lobbying for registration of drugs in-country; translation into Vietnamese and distribution of CAH educational resources; lobbying for the introduction of 17OHP blood testing; encouragement of the local CAH Support Club, and raising awareness nationally and internationally about the plight of this otherwise powerless group of people. The long-term working relationships between staff at Melbourne's Royal Children's Hospital (RCH), the Director of RCH International (RCHI) Professor Garry Warne, and the staff of the National Hospital of Pediatrics (NHP) in Hanoi were critical to CLAN's early acceptance by health professionals in Vietnam, and highlighted the importance of networking at an early stage in CLAN's development.

The achievements in Hanoi — and later Ho Chi Minh City — soon resulted in requests from health professionals in other countries for CLAN to support CAH families in the Philippines (2005), Indonesia (2006) and more recently Pakistan (2007). Whilst each country is culturally and politically unique, the core activities of CLAN have continued to focus on the five pillars, and the needs of CAH families around the world always seem more similar than disparate.



very much for the time she has put into CLAN over the years.

It has always been CLAN's vision that once urgent humanitarian needs are met, we constantly strive for long-term, sustainable, structural, policy and development-based activities so that our work can continue to benefit as many children and families as possible. Indeed, it is my hope that CLAN's future work will extend to help children living with other



In July 2007 CLAN was invited to help children living with diabetes in Vietnam. After attending a Diabetes Club meeting in Hanoi and learning more about the situation, it was clear that the plight of children diagnosed with diabetes in Vietnam was so severe that immediate action was imperative. CLAN's potential to use CAH as a pilot condition for other chronic medical conditions of childhood had already been considered, and it was encouraging how easily the five pillars transferred to diabetes. Again, collaboration with other parties has been the key to change.



chronic medical conditions besides CAH and diabetes, although we must balance expansion with effectiveness, and continually evaluate our work to ensure it is genuinely impacting on the lives of the children and families that we purport to help.

in isolation. Long-term change will require cross-sectoral and institutional collaboration on an unprecedented scale. I often speak of creating a "wheel" of interested participants, who are willing to come together as "spokes", united in their desire to see better health outcomes for the children. The more spokes, the rounder the wheel, and the faster and further it will roll.

CLAN would like to take the opportunity in this Annual Report to acknowledge the many people and organisations we have rolled along on this journey with so far, and encourage any others who may be interested to consider joining in what we hope will be an historic movement.

### CLAN INCORPORATED!

In light of this new and broader activity base, a subtle name change was made to CLAN (Caring & Living As Neighbours). In addition, the need for a more formalized structure became clear, and in December 2007 CLAN was officially Incorporated as an Association by the NSW Office of Fair Trading, Department of Commerce. At this point my sincere thanks must go to the committee of wonderful people who have come on board to help guide CLAN through this process (please see photos and individual introductions). We plan to formally launch CLAN as an independent organisation in 2008, but in the interim, CLAN's finances will continue to be generously managed by RCHI Business Development Manager Ms Helen Crawford, and we thank Helen

DR KATE ARMSTRONG  
B. Med DCH MPH

Founder & President  
CLAN (Caring & Living As Neighbours)

[www.cahclan.org](http://www.cahclan.org)  
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### WORKING AS A WHEEL



Helping children living with chronic medical conditions in resource-poor countries to enjoy happy and healthy lives is not sustainable when we work



CLAIRE HENDERSON  
Committee Member



LILEA PROPADALO  
Committee Member



PETER WATT  
Committee Member

# CAH HIGHLIGHTS

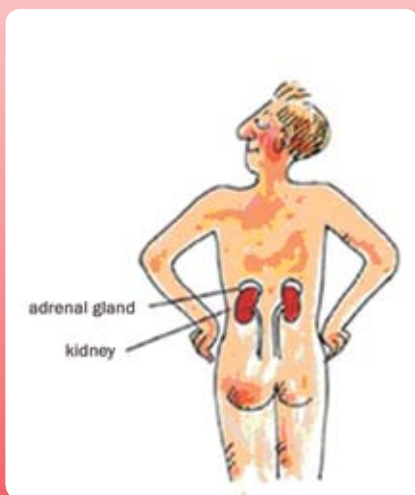
## Did you know ...

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.



Clipart reproduced with the kind permission of Prof Garry Warne.

*"I have struggled with CAH in different ways since diagnosis and though it became less of an overall influence, events during my treatment as a child have had long-lasting effects I am only aware of, even now.*

*CLAN benefits me as a healthy 38 year old with CAH, having had two children, one miscarriage and another baby due in April 2008. I have often lived with the negatives in my life and CLAN lets me focus on the positives. Sometimes I feel too much is made of my pregnancies and experiences, when there are so many other women with CAH also having children.*



*Being able to bring hope to other families through sharing my experiences (whereas many do not) brings me great joy and rewards me in a way possibly only I can understand."*

LILEA PROPADALO  
Committee Member

## TRANSLATIONS OF EDUCATIONAL RESOURCES

The booklet *Your Child with Congenital Adrenal Hyperplasia* by Prof Garry Warne was translated into Tagalog, with printed copies made available to Filipino families at the Club meeting in November. The book will be available online in 2008. In addition, the book was also made available online in Chinese characters for the first time. Further chapters of the more detailed book *CAH: A Parents' Guide* by C Y Hsu & Scott A Rivkees have been translated into Vietnamese, and this is a fantastic resource for everyone. CLAN has also made a copy of the book available to IKAHAK, in Surabaya. CLAN newsletters have also been made available to families in Bahasa, Tagalog and Vietnamese.

## CLAN'S FIRST DVD

Thanks to the extremely professional and talented film-makers Johnny Tran and Joanne Saad, CLAN was able to produce a 10 minute DVD that offers encouragement and support for families and young people living with CAH. The film shares the lives and thoughts of two Australians (Lilea Propadalo age 38, and Joe Hansen, age eight) who are living happy and healthy lives with CAH. Viewers can choose the English or Vietnamese versions, and a screening at the CAH Club meeting in HCM City was very positively received. We hope to have the film made available in other languages in the near future.

## JULY — CAH CLUB MEETING IN HANOI

As usual, a huge event, with over 300 people estimated to have attended. For families, the prime concern is always access to affordable medication. Latest updates from Bristol-Myers Squibb suggest that Florinef will be registered

by the end of 2008, and hydrocortisone tablets are already locally available, with the Ministry of Health allowing a Korean company to import their product.



In view of these developments, CLAN's future focus will shift from humanitarian donations of drugs to helping families afford the medication they will have to buy locally. As well as the usual educational focus this year, CLAN organised a social event for families in the evening, and invited several locally successful enterprise development and vocational training organisations to come along and speak with the families.

Catering of lunch and dinner by KOTO, a charitable organisation that offers vocational training in the hospitality industry for socially and economically disadvantaged youth was a more practical way of demonstrating to families the sort of opportunities that are available in Hanoi. Historically, 100% of KOTO graduates find well paid positions at the end of their 18 month training course.

## NOVEMBER — CAHSAPI MEETS IN MANILA

CAHSAPI, the CAH Club in the Philippines, had their third annual meeting, and it was a great success. The focus this year was on coping with the psychological burdens of CAH, and families report this was very helpful. Local access to hydrocortisone and fludrocortisone tablets is strongly on the agenda in Manila, and we hope 2008 will bring great things. In the interim, the Filipino Bureau of Food and Drugs has granted CLAN especial permission to send essential medication to doctors at the Philippines General Hospital, and for this we are very grateful.



## PFIZER DONATES SOLU-CORTEF



Sincere thanks to Pfizer for their help with accessing vials of Solu-Cortef and educational posters — these have been used to help families practice injection techniques, and start to familiarize themselves with optimal sick-day management.

## NEW CAH CLUB FOR INDONESIA – IKAHAK

Dr Muhammad Faizi, a compassionate and committed Paediatric Endocrinologist from Surabaya, East Java, first contacted CLAN in 2006, and urgent humanitarian donations of hydrocortisone, fludrocortisone and Solu-Cortef were arranged. An additional monetary donation was made to sponsor a local CAH Club, and in June 2007 IKAHAK was founded. The inaugural meeting of IKAHAK in Surabaya on 24th October 2007 was a fantastic achievement for all Indonesian CAH families, with plans afoot to start IKAHAK in Jakarta in 2008.



## LEARNING ABOUT PAKISTAN

After meeting personally with Dr Jamal Raza, one of only two Paediatric Endocrinologists in Pakistan, CLAN committed to sponsoring the role of an educator at the National Institute of Child Health, Karachi, to start in 2008. In December Peter Watt visited Karachi to learn more about the situation for children and families living with CAH in Pakistan. Whilst local benefactors generously help families access the medication they need, Florinef supplies have always been uncertain, and CLAN was pleased to help Dr Raza connect with local BMS representatives, to secure future availability.

## MY VISIT TO HCM

In November 2007, I went to Ho Chi Minh (HCM) city for the first time to visit the HCM CAH support group meeting. It was my second time in Vietnam, having visited the Hanoi CAH support group a few years earlier.

HCM city was certainly a surprise. It was a bustling, busy city which I found stimulating to the senses. The first thing I noticed in the city itself was the extremes of wealth versus poverty. The five star hotels, shops and restaurants were within kilometres of the poorest housing districts I've ever seen. And still the Vietnamese people were just as I remembered – friendly folk who are devoted to their families.

The Club meeting was held at Children's Hospital Number 1 (CH1). I found the meeting to be extremely well organised with a great deal of work having been done behind the scenes by parents and doctors. This year CLAN sponsored two people from Hanoi CAH group to travel to HCM (see photo below). From all reports, they found the meeting very informative. It gave them great ideas to implement into their own meeting, and this fits with CLAN's objectives – to share information, provide support and foster independence in people affected by chronic illnesses.

This year CLAN engaged the services of Sozo to provide catering and refreshments for the meeting. Sozo employs disadvantaged young people and teaches them hospitality skills. The team from Sozo also entertained the children in a separate room outside the meeting room. This was such a great idea as the parents could truly focus on the content of the meeting while their children were enjoying themselves with games and activities. I considered that a formula for success and something that could be considered for future CLAN support group meetings.

The sharing of stories and questions from parents is always a highlight for me. An opportunity to ask questions of a panel of doctors and parents is an invaluable way for everybody in the room to learn from each other. Those 'nagging' questions

were raised and answered. The parents were relieved to have answers to those questions, or to understand that they needed further information from their treating doctor.

Overall I considered the meeting a huge success and it was a credit to the hospital, families and CAH Club for their professional and welcoming approach. After the meeting, Kate and I visited various organisations in HCM to gather information and support to help the CAH families in HCM even more. We visited World Vision, the Australian Consulate, RMIT University and another NGO, Heartreach Australia. We also met with Dr Raza and discussed setting up a support group for CAH and Diabetes in Karachi. All of these meetings were very productive as we shared and received various network contacts and developed a greater understanding of the challenges faced by families with chronic illnesses.

The trip was a wonderful opportunity and I am honoured to have been part of the experience. As CLAN continues to grow, I expect that many more wonderful people and experiences will come into my life. And in return, I look forward to helping those families affected by chronic illness in resource-poor countries to the best of my ability.

MICHELE KONHEISER  
Vice President



### ALPHAPHARM DONATES HYSONE TABLETS

CLAN has been incredibly grateful for Alphapharm's ongoing support and donation of hydrocortisone tablets (Hysone) for use by our neighbours' children in Vietnam, the Philippines and Indonesia.



### BRISTOL-MYERS SQUIBB (BMS) DONATES FLORINEF TO VIETNAM

Thank you to BMS for generously donating Florinef for all children living with CAH in Vietnam for a three year period (2005-08). It has been a pleasure collaborating with them on this project.



# DIABETES HIGHLIGHTS

## Did you know ...

Diabetes Mellitus (DM) is a chronic medical condition, and it occurs when there is too much glucose in the blood. Blood glucose levels rise because the body is not producing insulin, or not using insulin properly. Insulin is a hormone that allows glucose in the blood to enter the body cells, so that it can be converted into energy.

In children, diabetes is usually caused by a failure of the pancreas to produce insulin. Known as Type 1 (T1DM) or insulin-dependent diabetes, it is one of the most common chronic conditions of childhood in developed countries. The cause of T1DM is not yet clearly understood.

Treatment of T1DM requires lifelong insulin injections, blood glucose monitoring, regular medical checks and healthy eating. In developed countries children with T1DM can expect a high quality of life, but unfortunately the cost of treatment is beyond the budget of most families in resource-poor countries. As a result, most of these children suffer terrible complications – including blindness and kidney failure - and mortality rates are also much higher than in developed countries.



## BETACHEK DONATES STRIPS

On hearing about the situation for children in Vietnam, Betachek made a donation of some glucose monitoring strips and negotiated a very reasonable price for ongoing access for families in Vietnam. The visual strips do not require expensive electronic meters, and so represent excellent value for families.



## LEARNING ABOUT DIABETES IN VIETNAM

In July CLAN attended the Diabetes Club meeting at NHP (National Hospital of Pediatrics) in Hanoi for the first time, and was deeply saddened by the plight of the children who are diagnosed with Type 1 Diabetes. The average annual income in Vietnam is US\$723 (2004), and this is not enough for most families to afford the treatment their children need to enjoy a good quality of life with diabetes. There is no support from the government for families, who often bankrupt themselves caring for their children. At NHP in July 2007:

- There were only 150 children currently receiving treatment for diabetes (NHP is the largest tertiary referral hospital for the whole of North Vietnam)
- Less than 10% of families can afford to monitor blood glucose levels
- 74% of children have complications at six years post-diagnosis (usually kidney and eye problems). One child was clearly blind on the day of the meeting, another had Mauriac's Syndrome
- No ketone testing; no access to glucagon
- There is at least one fatality a year
- Financial burdens are the greatest problem for families.

Some excerpts from Question and Answer Time at the Diabetes Club Meeting in Hanoi:

- Q: Young male teenager stands: "My family is poor, we cannot afford my insulin. What support is available to us?"
- A: "None" (the young man sat down quietly, accepting his fate with quiet dignity.)

Q: Young female teenager stands: "I was diagnosed with diabetes when I was 10. I am 18 now. Why don't my eyes work properly anymore?"

A: General discussion about the consequences longer term of high blood glucose levels.

## CLAN'S DIABETES PLAN

Given our experience with CAH, CLAN knew something could be done, and so within 48 hours of attending the Diabetes Club Meeting had drafted the CLAN Diabetes Plan, which has since been circulated to experts around the world, seeking help and collaborative efforts for the children in Vietnam.

## INSULIN DELIVERED TO CHILDREN'S HOSPITAL 1 (CH1)

When visiting HCM City for the CAH Club meeting in November, several friends of CLAN personally carried a six month supply of insulin for all the children in suitcases, and delivered it safely to CH1 Pharmacy Department on arrival. Families have been very happy with the supply - and the relief on their limited budgets.

## A DIABETES CLUB FOR CH1 IN 2008?

CLAN has received formal permission from Dr Thuong (Director of CH1) and Dr Loan (Head of the Endocrinology Ward at CH1) to start a Diabetes Club at CH1 in 2008. We hope the first meeting will run around the same time as the third Annual CAH Club meeting.

## TRANSLATION OF AN IMPORTANT DIABETES EDUCATIONAL RESOURCE INTO VIETMAESE

At the Diabetes Club meeting in Hanoi, CLAN learnt that there were no

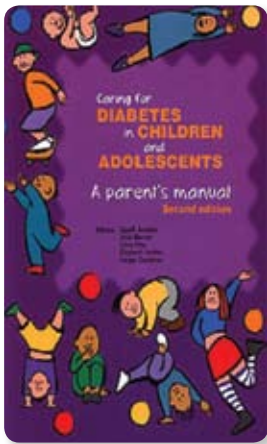
## COLLABORATION WITH INSULIN FOR LIFE (IFL)

IFL is an Australian-based charitable organisation that redirects unused insulin. When people living with diabetes in Australia and other more developed countries have supplies that they no longer need (for example, their doctors change their insulin prescription), they can choose to post them to IFL instead of throwing them away. These high-quality supplies can then be given free to people in resource-poor countries who need them to survive. Courier costs do need to be covered, but for CLAN, this has represented a very cost-effective way of helping children in Vietnam access urgent supplies of high quality insulin.



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

educational resources available to families in Vietnam on diabetes. In Australia and New Zealand, the parents of every child diagnosed with Diabetes will have been given a copy of the book



*Caring for Diabetes in Children and Adolescents: A parent's manual*. It is the gold standard for care, and the "purple bible" that everyone refers to when questions and problems arise.

CLAN is grateful to the authors of this book, who have generously given permission for the resource to be translated into Vietnamese. It is CLAN's dream that this resource is made as widely available as possible in Vietnam, and will help improve health outcomes longer term for the children.

## ENDOCRINE PROJECT DEVELOPMENT OFFICER

CLAN successfully applied to AusAID for an AYAD (Australian Youth Ambassadors for Development) for 2008 as an Endocrine Project Development Officer. Claire Henderson will start the role in March 2008, working with CLAN and the Endocrine Department at NHP, Hanoi to promote endocrine management strategies and networks, and liaise directly with NHP's family Support Groups (CAH and Diabetes) to explore long-term solutions to the many burdens they face. This will be an invaluable boost to our exploration of enterprise development



and vocational training opportunities in North Vietnam, as part of our long-term goal to help families achieve the financial independence they need to care for their children..

## THANK YOU NOVO NORDISK!

In July 2007, 80 staff from Novo Nordisk Australia traveled to Hanoi for their annual sales meeting. Prior to this visit, Novo staff had independently fundraised money to help children living with diabetes in Vietnam, and donated a substantial sum of money that has so far funded:

- Two diabetes nurse educators to travel from Australia to Hanoi to provide a short diabetes nurse training course
- Outfitting a Diabetes Counseling Room, located on the Endocrinology Ward at NHP
- Translation of purple manual *Caring for Diabetes in Children and Adolescents: A Parent's Manual* from English into Vietnamese.

CLAN believes these development activities will make a huge difference to health outcomes for children living with diabetes in Vietnam.



## DONATION OF DIABETES SUPPLIES

After attending the Diabetes Meeting in Hanoi in July 2008, supplies sent by CLAN to Vietnam for use by the 250 children receiving treatment for diabetes at the children's hospitals in Hanoi and Ho Chi Minh City so far include:

- 9,752mls of insulin
- 11,000 syringes
- 15,400 pen needles
- 5,000 strips
- 33 lancet pens
- 4,800 lancets; swabs and medical text books.

Sincere thanks to Insulin For Life who made this possible.

**StickyJewelry**  
www.stickyj.com

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.



# OUR NEIGHBOURHOOD



United Arab Emirates (Dubai)

Pakistan

*"My connection with CLAN started some 12 months ago after meeting CLAN representatives at a CAH seminar in Australia. Our five year old son, Joshua, has CAH so the current work of CLAN and its future goals and objectives is close to my heart.*

*Because my job involves a significant amount of international travel to many undeveloped countries, I appreciate the general poverty and lack of medical resources available.*

*Being able to meet doctors, parents and children exposed to CAH and diabetes, and help CLAN assist in achieving better care and support to impoverished children provides great satisfaction."*

PETER WATT  
Committee Member  
(Currently living in Dubai)

*Thank you* to all the health professionals that CLAN has had the privilege of working with over the years. It is your compassion for the families and commitment to improving the health outcomes of the children that makes anything possible.

## THANK YOU TO OUR INDIVIDUAL SPONSORS!

Alison Pyke, Andre Grassy, Ann Maguire, Anne Craighead, Ashley Wilson, Belinda Moore, Bill McPaul, Brian Jones, Bruce Peters, Carmen Risk, Catherine Kay, Cathy Hassarati, Charmaine Tam, Chris Cowell, Craig Gerlach, Graig Munns, D E & M R Hansen, Duncan Langmead, Endo & Diabetes staff: Westmead Children's Hospital, Gerald V Reed, Glenda Fraser, God's Squad CMC Newcastle, God's Squad CMC Sydney, Gordon Green, Greg Hirst, Harald Sondergaard + Cassons Pty Ltd, James Cox, Janine Cusumano, JB Friel, Jeanette Lock, Jenny Lee, Jim Minchenko, John Brumpton, Karen Nieuwendyk, Kecia Taylor, Kerrie Barker, Kim Martin, Lindy Batchelor, Liz Lawrie, Lourdes Rintale, Luke Davie, Lynne Foxall, M Bean, M P Caldecott, Margaret Couri, Margaret Lloyd, Maria Craig, Megan Batchelor, Michael P Cavanagh, Michele Konheiser, Nathan Johnson, Nicole Matthews, Oksana Markovych, Owen Lukins, Paul Benito, Paul Johnson, Paul Kelly, Paul Kitson, Peter Starkey, Rob & Val Wiebe, Rob Worthington, Ronda Greaves & Mark Maunder, Russell Pritchard, Sarah Garnett, Shubha Srinivasan, Simone Kelly, Stephan Henderson, Steve Chance, Steve Davie, Steve Jones, Stewart Birt, Suzanne Forwood, Trevuren Electronics Design, Various donations, Vaughan Bowie, Westmead Donations (Endo & Diabetes), and Westpac / Matched donations.





## REPORTING BACK TO APPES MEMBERS

In 2006 CLAN attended the Asia Pacific Pediatric Endocrinology Society conference in Thailand, and conducted a survey of members regarding CAH and access to medication. The survey results were very interesting, highlighting the difficulties shared by many, and we are grateful to APPES for publishing our report in their March 2007 Newsletter.

## NEWBORN SCREENING (NBS) FOR CAH

In 2007, a trial of NBS for CAH at Tu Du Hospital in HCM City has been very successful, with six children diagnosed with CAH through the pilot program. Ironically, Australia is yet to start screening for CAH, but CLAN is very pleased to support the APEG (Australasian Pediatric Endocrinology Group) CAH Working Group in its efforts to introduce CAH screening into Australia.

Australia really lags behind its neighbours in this realm — New Zealand already screens for CAH, as does the Philippines. CLAN was proud to sponsor a Filipino paediatric endocrinology fellow to attend a NBS Conference held in Singapore in August.

*"I have worked as a General Practitioner for 20 years, based in the Melbourne metropolitan area. My focus at work is mainly paediatrics and women's health.*

*I am married to David Healy and together we have two daughters aged 19 and 21 and a son aged 17 who has CAH. We are very fortunate that our son has had the clinical care of Dr Garry Warne and the Royal Children's Hospital, Melbourne and we are very aware that there are many children who do not have access to such expertise.*

*I feel very privileged to be associated with CLAN and I am hopeful of using my experience as a doctor and as the mother of a child with CAH, to improve the lives of less fortunate children."*

DR SUE DITCHFIELD  
Committee Member



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**serono**  
biotech & beyond



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.

# FUNDRAISING

*Would you like to know more about CLAN?*

*Please visit us at:  
[www.cahclan.org](http://www.cahclan.org)*

***"It is with great excitement that I take on this new role with CLAN. It isn't every day that such a unique opportunity gets presented to you, and I am pleased to offer my business and book-keeping skills to a cause that so clearly makes a vast difference to people's lives.***

***I am keen to contribute my time and know-how to CLAN, supporting those committee members who are working with families at the 'front-line'. In addition to my accounting and legal skills, I offer to CLAN my firm belief that we are making a positive difference not just for today but also for tomorrow."***

**HEIDI ARMSTRONG**  
Treasurer

***"I have been employed in a government organisation for the past 25 years and through this experience I have developed a number of skills that can be utilised in nurturing CLAN's growth and supporting people affected by life threatening health conditions.***

***My official role for CLAN is association Secretary, primarily to assist with the organisation, management and administration of the association for CLAN, in particular: developing agendas and minutes of meetings; developing and maintaining operating procedures; facilitation of consultative committees; and other similar duties. I am delighted to be part of CLAN. It is personally fulfilling to be part of a group, which is internationally represented, where like-minded people are working together to help those in need."***

**CATH COLE**  
Secretary



## DO YOU HAVE ANY FUNDRAISING IDEAS?

CLAN's work is not limited by ideas or need! We are so grateful to all of our wonderful sponsors and donors, because it is only through your generosity that we are able to operate.

Any and all financial contributions are very gratefully received by CLAN, and we commit to report back each year with a transparent review of how all monies are spent.

Please do not hesitate to contact CLAN if you would like to help with fundraising. Heidi Armstrong would be happy to help with any enquiries at: [info@cahclan.org](mailto:info@cahclan.org)

## FUNDRAISING WITH A DIFFERENCE!

On 11th August 2007, Steve Jones (better known as 'Fish' to his mates in God's Squad Motor Cycle Club) celebrated his 50th birthday.

In lieu of gifts, Fish asked party guests to part with cash as he shaved his beloved beard off for the first time in over 30 years! All monies raised were donated to CLAN, and we are thrilled to say that over A\$2,000 was raised on the night.

Thank you so much to Fish, his family and friends for such a generous gesture. CLAN could not operate without the help of all our donors and sponsors who care about our neighbours overseas.



[www.sydney.gscmc.com.au](http://www.sydney.gscmc.com.au)



BEFORE



AFTER!

## PLEASE CONSIDER WHAT YOU CAN DO TO HELP

*"How wonderful it is that nobody need wait a single moment before starting to improve the world."*  
Anne Frank

*"Act as if what you do makes a difference. It does."* William James

*"Unless someone like you cares a whole awful lot, nothing is going to get better. It's not."* Dr Seuss

*"I am only one, but I am one. I cannot do everything, but I can do something. And I will not let what I cannot do interfere with what I can do."* Edward Everett Hale

# FINANCIALS

## CLAN STATEMENT OF FINANCIAL PERFORMANCE

<p>1. REVENUES</p> <p>Balance brought forward (2006)..... \$13,000.95</p> <p>Monies received as donations ..... \$22,741.77</p> <p>Interest received on donations ..... \$723.09</p> <p>Total Revenues ..... \$36,465.81</p> <p>2. EXPENSES</p> <p>CLAN overseas travel ..... \$1,150.00</p> <p>Sponsorship of overseas meetings and events. . \$5,534.68</p>	<p><i>EXPENSES CONTINUED</i></p> <p>Translation expenses..... \$4,254.34</p> <p>Production of multimedia materials ..... \$2,500.00</p> <p>RCHI Facility Fees ..... \$112.00</p> <p>Total Expenses..... \$13,551.02</p> <p>3. BALANCE AT END OF YEAR ..... \$22,914.79</p>
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*Notes: Refer to CLAN Statement of "In-Kind" Provision of Services.*

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

Provider	Expense Category	Estimated Value	Comments
Individuals	Courier expenses	\$2,317.55	Sending medications and supplies overseas
Individuals	Courier expenses	\$2,186.00	Medication from IFL: Diabetes, Vietnam
Individuals	Courier expenses	\$207.00	Sundry postal expenses (Australia Post)
Individuals	Communication	\$77.51	Hot Air Conferencing (CLAN committee meeting)
Individuals	Educational Resources	\$150.00	Purchase of books / resources to send overseas
Individuals	Educational Resources	\$170.00	Reproduction of Multimedia Materials, DVD
Pfizer	Materials purchases - medications	\$160.00	Solu-Cortef: Donations to Philippines & Vietnam
Alphapharm	Materials purchases - medications	\$5,639.00	Hysone: Donations to Indonesia, Philippines & Vietnam
Bristol-Myers Squibb	Materials purchases - medications	\$2,220.00	Florinef: Donations to Vietnam
Individuals	Materials purchases - medications	\$1,435.01	Purchase of medications: CAH
Betachek	Materials purchases - medical supplies	\$300.00	Glucose monitoring strips to Vietnam
Sticky J	Medical ID Bracelets	\$1,000.00	Donated free for Diabetes and CAH Patients
Individuals	Medical ID Bracelets	\$900.00	For Diabetes and CAH Patients
Individuals	Sponsorship of overseas meetings and events	\$2,183.11	Catering by KOTO for CAH Club, Hanoi Vietnam
Individuals	Sponsorship of overseas meetings and events	\$150.00	Small gifts for children attending overseas events
Individuals	Printing and stationary	\$530.97	Sundry printing; stationary; email
Individuals	Printing and stationary	\$1,745.00	Production and printing of Annual Report and brochures
Mal Salmon	Professional consultancy	\$250.00	Graphic design
Jane Louise Creations	Professional consultancy	\$500.00	Graphic design — Annual Report
Individuals	Professional consultancy	\$2,316.75	Incorporation expenses
Butlers	Professional consultancy	\$2,000.00	Incorporation advice — Butlers Taxation & Business Advisers
Individuals	Training and development	\$2,150.00	Study expenses — Asialink, University of Melbourne
Individuals	Travel	\$2,727.18	Travel: airfares and accomodation expenses
RCHI	Travel	\$1,500.00	Travel: support with airfares to Vietnam
	<b>TOTAL</b>	<b>\$32,815.08</b>	

Notes: Volunteers have contributed hundreds of hours of support to CLAN.



**PROFESSOR GARRY WARNE**  
Senior Endocrinologist  
Director of RCHI



**HELEN CRAWFORD**  
Finance Officer  
Business Development Manager, RCHI

CLAN is very grateful to the wonderful team at RCHI (Royal Children's Hospital International) for the support they have given us over the years. Professor Garry Warne's long-term relationships with colleagues in Vietnam have had a tremendous hand in our success there so far, particularly with his kind attendance at CAH Club meetings over the years. Likewise, Helen Crawford's patience and generosity of spirit in managing CLAN's accounts has been invaluable, and we cannot thank her enough for the time and effort she has put into CLAN over and above her own work duties.

# Let's grow together in 2008



*"You must be the  
change you wish to  
see in the world."*  
Mahatma Ghandi



Thank you for your  
generous support  
during 2007

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

*Any donation to CLAN will be joyfully accepted!*

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