

Clan annual report

Year Ending 31 December 2006

CLAN is a project managed by The Royal Children's Hospital Foundation Limited

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CAH Living As Neighbours

(CAH - CONGENITAL ADRENAL HYPERPLASIA)

Maximizing quality of life for all CAH patients by supporting:

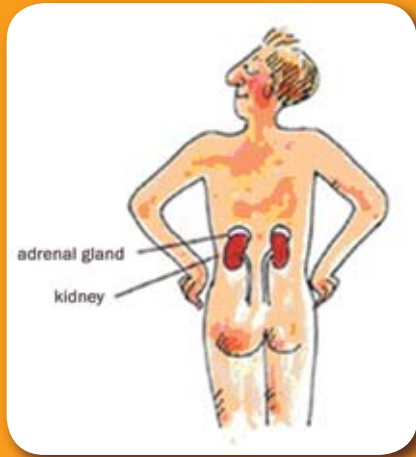
- Access to affordable medication
- Optimal medical treatment and
- CAH support group networks

so that all members of the international CAH community can enjoy healthy and happy lives, and know that their neighbours care.

www.cahclan.org

www.cahclan.org

info@cahclan.org



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.



HYSONE (hydrocortisone) tablets by Alphapharm.

FLORINEF (fludrocortisone) tablets by Bristol-Myers Squibb.

Clipart reproduced with the kind permission of Prof Garry Warne.

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What is CLAN?

CLAN (CAH Living As Neighbours) is an Australian-based charitable organization that is committed to helping all CAH patients of the world – especially children in developing countries – to enjoy the highest quality of life possible. CLAN's affiliation with the Royal Children's Hospital of Melbourne - specifically its charitable foundation **Royal Children's Hospital International (RCHI)** - not only ensures donations are tax deductible, but also allows for consultation with staff at one of the world's leading centres of excellence in the management of CAH.

The five pillars of CLAN

CLAN believes the best way to help children and families living with CAH in resource-poor countries is through:

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



*"We must not only give what we have;
we must also give what we are."*

Desire-Joseph Mercier



FOUNDERS' REPORT

Kate and David Hansen



DR KATE ARMSTRONG

(Mrs Kate Hansen)
General Practitioner

DAVID HANSEN

Manufacturing Manager

Kate and David have three young children. Their eldest son has CAH.

It is with tremendous gratitude that we write this introduction for CLAN's second-ever Annual Report. Even in a few short years there has been enormous change for children living with CAH in the Asia-Pacific region, and none of it would have been possible without the wonderful, amazing people that have walked with us on the journey so far.

Most notably, the situation for children in Vietnam, the Philippines and now East Java, Indonesia is transforming on an historic scale. Paediatric endocrinologists in all of these countries have bravely stepped out and worked above and beyond their duties to effect change that is literally life saving.

Their selfless collaboration and generosity has been matched by a myriad of hospital directors and pharmacy departments, government and customs officials, philanthropic organizations and existing CAH support groups, generous donors and sponsors, committed family members and dedicated adults living with CAH across the globe



who have similarly contributed their energy and talents, all with incredible effect.

As word spreads, newcomers are being swept up by the momentum that is now carrying us all forward, changing the landscape forever.

CLAN was thrilled to collaborate with doctors in Hanoi and Prof Garry Warne from the Royal Children's Hospital International to publish an article on CAH in Vietnam in the prestigious Journal of Pediatric Endocrinology and Metabolism. This is the first time an article specifically addressing the issues of CAH and poverty has appeared in the international literature.

Likewise, CLAN's attendance at the Asia Pacific Pediatric Endocrinology Society's biannual conference (held in Pattaya, Thailand) was another excellent opportunity to network with doctors from around the region. We hope that our survey of attending delegates will continue to raise international awareness of the difficulties CAH families in resource-poor countries face on a daily basis.

Moving forward, CLAN will continue to strive for improved global equity for all children living with CAH. It is a great privilege to work for these young people – our neighbours – who have previously suffered in silence and isolation.

Please accept our most sincere thanks to all for your ongoing support and collaboration. ■



"Kindness is the language which the deaf can hear and the blind can see."

Mark Twain

MICHELE KONHEISER CLAN Newsletter Editor and Fundraiser

After visiting Hanoi in 2004 and seeing first hand the situation for CAH families, Michele continues to commit her time and energy to CLAN. Now responsible for production of a regular newsletter, Michele will become the face of CLAN to hundreds of CAH families abroad. Only a very small percentage of families have access to the internet, so CLAN seeks to overcome their isolation by ensuring CAH news and updates reaches them in the post instead.



"I was fortunate to visit Hanoi in June 2004 with my daughter (who has CAH), my husband and my son. It was very touching to meet and talk with families who lived with CAH and to discuss the challenges that we sometimes face."

HIGHLIGHTS



Affordable Access to Medication

CLAN works with Bristol-Myers Squibb and Alphapharm to ensure drugs reliably available to all children with CAH in Vietnam and the Philippines. Currently over 500 children!



APPES Conference in Pattaya, Thailand

CLAN attends the biannual Asia-Pacific Pediatric Endocrinology Society Conference held in Thailand. Survey of doctors helps us learn more about CAH in the region.



New CAH Club in Ho Chi Minh City

Inaugural meeting for CAH families in HCM held in November 2006. Survey of parents conducted by local doctors and parents.

Another excellent resource for families

Permission received from American Paediatric Endocrinologist, Scott Rivkees, and parent Carol Hsu, for CLAN to translate their fantastic book on CAH into Tagalog and Vietnamese.

Drugs to Indonesia

Collaborating with a compassionate and committed doctor in East Java, CLAN is now providing free medication to a small group of children with CAH in Indonesia.

Free Florinef in Vietnam

Bristol-Myers Squibb continues to honour its very generous commitment to provide free Florinef to all Vietnamese CAH patients for three years as they work towards registration.

Hydrocortisone is now available in Vietnam!

The National Hospital of Pediatrics in Hanoi has now successfully arranged for importation of hydrocortisone into Vietnam for CAH in-patients. Registration is still pending.

17OHP testing now available in Vietnam

Doctors in Ho Chi Minh City initiated 17OHP blood tests for CAH patients, and Hanoi started very soon after. This is an essential tool in CAH management.

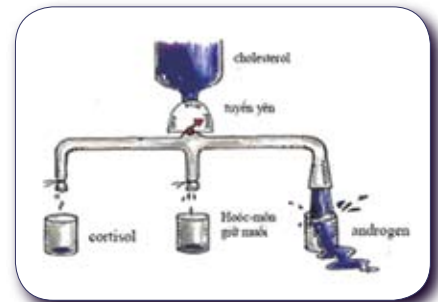
CAHSAPI Meeting

Second annual CAH Club meeting held at the Philippines General Hospital in Manila. Results of 2005 survey communicated back to families.



Hanoi CAH Support Group Meeting

Over 300 people attended this meeting, held at the National Hospital of Pediatrics in Hanoi. CLAN meets with Hanoi CAH Club executive to discuss future plans.



Booklet on CAH in Vietnamese

An updated Vietnamese version of Professor Garry Warne's booklet, *Your Child with CAH* was published and distributed for free to families in Hanoi and HCM.

Individual Web-sites for CAH Clubs

CLAN's web-site expands to include individual sites for each new Club, allowing all text to be in local language, and input by interested locals.

Health Professionals learning about CAH

Thanks to the efforts of doctors working in HCM and Manila, educational seminars on CAH have been held for local health care professionals, to raise general awareness and knowledge of CAH. ■

IMPRESSIONS OF HO CHI MINH

As I flew over to Ho Chi Minh City, I could not help but consider the effort put in by the staff at Children's Hospital No 1, in particular Dr Nguyen Bich Phuong, who organised both a CAH support group meeting and health professional study day. Organising one of these meetings would have been a tremendous task. However, it was elected to hold both for the first year in 2006. It was immensely encouraging to be part of a health professional's study day, focused solely on CAH. The study day provided the opportunity to liaise with various health professionals who care for children with CAH and to consider the greater needs of families with CAH.



CAH is a relatively newly recognised condition in the south of Vietnam and as a result families understandably are apprehensive as to what CAH means, for the short and long term outcomes of their child. During the support group meeting the valuable opportunity arose for families to raise questions about their children. This question time highlighted the importance of addressing the issues of gender and sexuality, not just the need to obtain medications and provide medical treatment.

Despite the language barrier, with such a condition there is very much an unspoken connection already established. On several occasions I was able to meet with one mother, who was able to speak English. Through her inspiring support and work with CLAN and the CAH support group, we will be able to reach out further to bring the CAH community closer together, within the south of Vietnam. Importantly we must remember the differences in culture and the potential fear when it comes to medical treatments. CLAN's links with both the community members and health professionals will enable us to take into account such considerations. ■



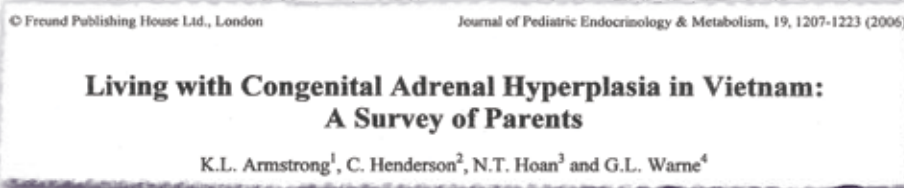
CLAIRE HENDERSON
Project officer
Diabetes Clinical Nurse
Consultant

"I was delighted to be able to meet up with the families who attended the CAH support group."

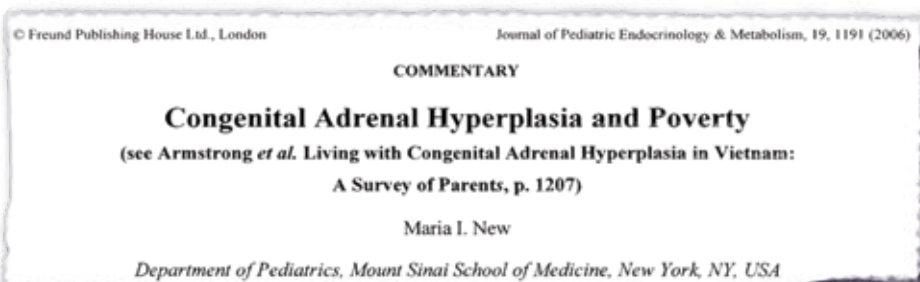
As an Australian (and Scottish!) adult living with CAH, Claire has an especial heart for the lives of children in resource-poor countries that CLAN is involved with.

Claire has now traveled to Hanoi, HCM City and Manila to meet with CAH families. Claire has brought untold hope, joy and encouragement to these families, and we thank her most sincerely for her generosity of spirit.

International journal publishes article on CAH in Vietnam



Results of CLAN's 2005 survey of parents attending Hanoi CAH Club meeting in 2005 published in *Journal of Pediatric Endocrinology & Metabolism*, raising international awareness of issues surrounding CAH and poverty. The accompanying commentary on our article by Prof Maria New, an internationally renowned expert on CAH, was very encouraging, and concluded, "Bravo! To the group in Australia for this pioneer report."



Distribution of MedicAlert bracelets

Thanks to MedicAlert, CLAN has continued to distribute these beautiful stainless steel bracelets to children with CAH in resource-poor countries.



PROF GARRY WARNE
Senior Endocrinologist
Director of RCHI

"The future holds many more exciting developments for CAH families in Vietnam."

- RCH Melbourne has commenced internet-based video conferences with doctors in Hanoi. This will be of great relevance in terms of bringing parent support organizations together with little expense.
- Tu Du Hospital for mothers and children in Ho Chi Minh (HCM) City (one of the largest obstetric hospitals in the world) intends to start a pilot study of CAH newborn screening early in 2007.
- Dr Nguyen Bich Phuong has decided to commence a PhD in 2007 and it will be on CAH. She will be spending some of 2007 studying in Melbourne at RCH.
- We are discussing ways of introducing prenatal treatment for CAH in the Vietnamese context of limited diagnostic capacity.

RCHI REPORT

Effecting Change in Vietnam

Prof Garry Warne

Royal Children's Hospital International (RCHI) is the Philanthropic arm of RCH, Melbourne, and we have been collaborating with the National Hospital of Pediatrics in Hanoi, Vietnam for many years now. We can think of nothing more important than achieving greater equity for the poor. It is a tragedy that many poorly resourced countries lack even the simplest essential drugs for treating CAH. So it is good to see that much progress is being made for children with CAH in Vietnam. Affordable access to medication



is essential, and thanks to CLAN, Bristol Myers Squibb (BMS) and Alphapharm, all children being treated for CAH in Vietnam have recently enjoyed free access to hydrocortisone (Hysone) and fludrocortisone (Florinef). In the near future, it is planned that progress towards registration of these essential medications will continue.

Vietnamese guidelines for the management of CAH have been written by Dr Nguyen Bich Phuong (HCM City), and established assays for 17OHP are now available in HCM and Hanoi. My little book "Your child with CAH" has been translated into both Vietnamese and Chinese <<http://www.wch.org.au/cah%20book/index.cfm?doc%20id=1375>> and both are available online. The Vietnamese version has been printed in Vietnam. Dr Phuong has also made wall posters to raise awareness of CAH amongst staff working in birthing

units when a baby with ambiguous genitalia is born.

In November, RCHI sponsored a CAH Workshop for 107 doctors (paediatricians, obstetricians and gynaecologists, psychiatrists, endocrinologists, neonatologists) and nurses at Children's Hospital No.1 (CH1) in HCM City. All lectures were translated, collated and distributed in the form of a handbook to participants.

CH1, CLAN and RCHI jointly sponsored a parents' meeting to inaugurate a CAH Support Club for the south of Vietnam. Over 100 parents attended. Each family received a copy of my book in Vietnamese. CLAN has also provided money to allow them to develop a newsletter and to hold their own meetings.

My colleagues in Indonesia have heard what is happening in Vietnam and they are keen not to be left out. The paediatricians in Yogyakarta are getting themselves ready to implement strategies used in Vietnam and they have the capacity. My book on CAH has now been



translated into Bahasa Indonesia (and a Bahasa Malay version is also in preparation). A Tagalog translation for the Philippines is in the pipeline and much has changed for CAH patients there also. RCHI welcomes ongoing collaboration with CLAN, and aims for continued improvements in health outcomes for CAH families in the Asia-Pacific Region. ■

FINANCIALS

CLAN Statement of Financial Performance

1. Revenues		
Balance brought forward (2005)	\$10,446.49	
Monies received as donations	\$11,245.20	
Interest received on donations	\$288.71	
	<i>Total Revenues</i>	\$21,980.40
2. Expenses		
Purchase and shipment of medications for overseas distribution	\$2,943.08	
Sponsorship of overseas meetings: Phillipines & Vietnam	\$1,045.00	
Translation expenses: Tagalog & Vietnamese	\$3,576.05	
Printing and Stationary Expenses	\$211.00	
RCHI Facility Fees	\$637.50	
	<i>Total Expenses</i>	\$8,412.63
3. Balance at End of Year		<u>\$13,567.77</u>

Notes: Refer to CLAN Statement of "In-Kind" Provision of Services.

CLAN Statement of "In-Kind" Provision of Services

Item	Provider	Estimated Value	Expense category, if paid
Purchase of Laptop for CLAN use	Individuals	\$2,932.90	Office equipment
Purchase and distribute books and other resources	Individuals	\$70.95	Materials purchases: books/resources
Sundry printing, stationary and email	Individuals	\$589.41	Printing and stationary
Graphic design for Annual Report and Web sites	Individuals	\$900.00	Professional Consultancy
Statistical analysis and support for article	Individuals	\$350.00	Professional Consultancy
Printing, Annual Report and Brochures	Kwik-Kopy Auburn	\$800.00	Printing and stationary
Printing, CLAN business cards	Mal Salmon	\$100.00	Materials purchases: other
Medications - donation to Vietnam and Indonesia	Alphapharm	\$4,400.00	Materials purchases: medications
Medications - donation to Vietnam	Bristol-Myers Squibb	\$6,000.00	Materials purchases: medications
Medications - sundry drug purchases and shipment	Individuals	\$1,469.21	Materials purchases: medications
Pens for CLAN Logo applications	ORSO	\$400.00	Materials purchases: other
Photography expenses photo development	Individuals	\$221.53	Printing and stationary
Postal Expenses	Individuals	\$182.10	Printing and stationary
Travel: airfares and accommodation expenses	Individuals	\$6,151.00	Travel
Estimated Total		<u>\$24,567.10</u>	

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



HELEN CRAWFORD
Finance Officer
Business Development
Manager, RCHI

All donations to CLAN are handled by RCHI and we are grateful to Helen for the time and effort she generously commits.



"The great thing in this world is not so much where we are, but in what direction we are moving."

Oliver Wendell Holmes



WE WOULD LIKE TO THANK OUR GENEROUS SPONSORS AND DONORS



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Any donation to CLAN will be joyfully accepted!



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