

clan

ANNUAL REPORT

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

Year Ending 31 December 2005

ACN 007 143 142 ABN 15 007 143 142



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

Contents

| | |
|--|---|
| Introduction to CLAN | 3 |
| Founders' Report | 3 |
| Highlights | 4 |
| Fruitful Collaboration Between RCHI and CLAN | 5 |
| Financials..... | 6 |
| The Price of Freedom | 7 |
| Sponsors and Donors | 8 |



Congenital Adrenal Hyperlasia (CAH) is an inherited condition in which children are born missing an enzyme in their adrenal glands. Because of this enzyme deficiency, affected children are dependent on the daily replacement of two hormones (ideally as tablet formulations of hydrocortisone and fludrocortisone) for survival. Happily, with the correct doses, children with CAH should expect to enjoy long and healthy lives.



In resource-poor countries, such tablets are not affordably available. Families struggle to afford the medication they need for their child to live and many children die, or suffer the terrible side-effects of poorly controlled CAH.



CLAN (CAH Living as Neighbours) is an Australian-based charitable organisation 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 - specially 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.



Introduction to CLAN

www.cahclan.org

info@cahclan.org



< **Dr Kate Armstrong**
(Mrs Kate Hansen)
CO-FOUNDER & DIRECTOR of CLAN
General Practitioner

< **David Hansen**
CO-FOUNDER OF CLAN
Manufacturing Manager

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

Prof Garry Warne >
DIRECTOR of RCHI
*Senior Endocrinologist,
RCH, Melbourne*



< **Claire Henderson**
PROJECTS OFFICER
*Clinical Nurse Consultant,
specialising in Diabetes*

Claire is a first-hand CAH expert!

Helen Crawford >
FINANCE OFFICER
*Business Development
Manager, RCHI*



Michele Konheiser
> FUNDRAISER

Michele has a daughter with CAH. The Konheiser family visited Vietnam in 2004. Michele's inspiring article about their experience helped CLAN to start.



Founders' Report

In late 2004, after reading articles on the desperate plight of families living with CAH in Vietnam, we were determined to effect change. By early 2005 the organisation **CLAN (CAH Living As Neighbours)** was operational, driven by a dream to unite the International CAH Community, and ease the burden of members who suffer tremendously in resource-poor countries.

CLAN gained rapid momentum and strong support from many quarters: health professionals; pharmaceutical companies; CAH Support Groups in the UK, NZ, US and Canada; individuals and families living with CAH; and friends, relatives and strangers who all believed in the concept, and helped make change a reality.



Although CLAN's growth was fast, it also occurred on a very firm foundation. Development of an early strategic plan ensured that all activities were to build upon one of CLAN's five organisational pillars: affordable access to medication; education; optimisation of medical treatment; encouragement of CAH Support Groups; and reduction of the financial burden of CAH that leads to poverty.

In one year CLAN has already achieved so much. Perhaps a real highlight is that medication is now affordably available to all children with CAH in North Vietnam and the Philippines. Whilst long-term solutions - such as



the registration of hydrocortisone and fludrocortisone in these countries - remain firmly on the agenda, we are proud that it won't be patients and families who carry the burden until these aims are achieved.

Of course, little would have been possible without our generous sponsors and donors, to whom we are most sincerely grateful. With their support, we will continue to focus on our strategic goals, aiming not only to expand CLAN's activities, but also to consolidate on activities already underway. Together, we believe that we will continue to effect change for good for CAH families around the world.

Kate and David Hansen

Highlights

Hanoi CAH Support Group Meeting

CLAN sponsors and attends this event in June 2005, offering support and solidarity.

Hope and Encouragement

CLAN sponsors Ms Claire Henderson to attend Hanoi CAH Support Group meeting. Claire not only works as an Endocrinology Nursing Specialist, but also has CAH, and proved a huge inspiration and encouragement to families and patients in Hanoi.

Filipino CAH Support Group Starts up

CLAN attends the inaugural meeting in Manila on 11 December 2005, and donates resources (booklets, bracelets etc) to families and patients.

Questionnaire for CAH Families in Hanoi

CLAN funds needs analysis of attendees at the Hanoi CAH Support Group meeting in June 2005. Results are communicated back to doctors and families, and also made available on CLAN's website.

Information on CAH Translated

CLAN's website is developed to include information on CAH in Vietnamese and Tagalog (Filipino language). www.cahclan.org

MediAlert Australia Donates Bracelets

300 high quality stainless steel bracelets donated to CLAN for distribution to children with CAH in resource poor countries. The need for hydrocortisone in emergency is inscribed on each bracelet. These are joyfully received!

Serono Australia's Booklets on CAH

Donation of 120 booklets on CAH to CLAN for distribution to families in resource poor countries.

Registration of Florinef

Bristol-Myers Squibb will try and register Florinef in Vietnam and the Philippines. Also open to other countries in the future.

Free Florinef Tablets in Vietnam

Bristol-Myers Squibb will donate free Florinef (fludrocortisone) for all Vietnamese children with CAH for the next three years.



Free Hysone Tablets in North Vietnam

Alphapharm donates free Hysone (hydrocortisone) for all children with CAH at NHP (the National Hospital of Pediatrics in Hanoi) for the next two years.



Affordable Access to Hysone

Alphapharm liaises directly with CLAN to ensure Hysone tablets are affordably available to all CAH patients in the Philippines and other countries where it is not yet registered for sale.



CLAN Sponsors New Filipino CAH Group

Donations from CLAN will enable this new group to access medication and resources needed to maximize support for CAH families in the Philippines.

Free Hysone and Florinef for Filipino Patients

CLAN donates one year's worth of free Hysone and Florinef tablets for all paediatric CAH patients at PGH (Philippines General Hospital), and will continue to support affordable access to same.



Promotion and Networking

CLAN develops pamphlets, business cards and posters to help with networking and promotion of activities.

Networking extensively with international CAH Support Groups, and had articles published in newsletters overseas.



Fruitful Collaboration Between RCHI and CLAN



Prof Garry Warne (Director of RCHI) is awarded the People's Health Medal, Nov 2005, Vietnam

with CAH and related conditions. There are paediatric endocrinologists in both Hanoi and Ho Chi Minh City and we are working with both centres to improve the management of CAH.

Doctors in Vietnam don't often think of CAH when they see a baby with ambiguous genitalia. They, and also the parents, are anxious about treating children with steroids such as hydrocortisone because they fear the side effects. When a child with CAH gets sick, the parents and some doctors may stop the hydrocortisone instead of increasing it, thinking that the child has enough problems without the drug making the illness worse.



Ho Chi Minh City has very recently established Vietnam's first assay for 17 hydroxyprogesterone and it is wonderful that Dr Nguyen Bich Phuong is currently spending two months at RCH Melbourne, sponsored by RCHI, to study our management of CAH. Parent information literature has been translated into Vietnamese and is available on-line.

CLAN has done a wonderful job in engaging pharmaceutical companies like Bristol-Myers Squibb (BMS) and we are thrilled that BMS is now in the process of registering Florinef in Vietnam.

In the interim, they are donating Florinef for Vietnamese children with CAH. CLAN and RCHI have worked together to support the Vietnamese CAH Club. Attendance by Kate Hansen and Claire Henderson at the 2005 meeting in Hanoi was profoundly appreciated by the 100 Vietnamese families who came to meet them. RCHI has made efforts to improve gynaecological services for girls with ambiguous genitalia due to CAH. Two RCH gynaecologists, A/Prof Sonia Grover and Dr Yasmin Jayasinghe have journeyed to Hanoi to see patients and meet their colleagues, and Hanoi gynaecologist, Dr Nguyen Thi Tan Sinh, was guest at RCH Melbourne in November. In 2006, further medical education activities will be undertaken in Vietnam. In addition, it is our intention to facilitate the distribution of Florinef throughout the country with the assistance of the Vietnam Paediatric Association and to continue to lobby for the addition of hydrocortisone to the list of officially sanctioned medications, so that cheap and reliable supplies reach those who most need it.



RCHI welcomes collaboration with CLAN in support group activities for families, in fundraising and in its strong advocacy role.

Thanks CLAN!

*Prof Garry Warne
Director of RCHI*

19 February 2006

It's great that CLAN has thrown its considerable energy into helping children with CAH who live in resource-poor countries like Vietnam and the Philippines. In a very short time, CLAN has achieved outstanding results. My organisation, Royal Children's Hospital International, or RCHI (pronounced "Archie") appreciates the help that



CLAN can give and the two organisations have shown themselves able to work very well together. RCHI (http://www.rch.org.au/rchi/index.cfm?doc_id=803) aims to mobilise and co-ordinate the resources built up over more than a century at one of Australia's finest children's hospitals and make them available for development aid projects. All of the funding for this activity comes from philanthropic donations.

Our main sponsor, Atlantic Philanthropies (<http://www.atlanticphilanthropies.org/index.asp>) has a particular interest in Vietnam and hence most of our projects are based there. I have been visiting that country for ten years and as an endocrinologist, I have taken a particular interest in the fate of Vietnamese children

Financials

CLAN Statement of Financial Performance

1. Revenues

| | |
|-------------------------------------|--------------------|
| Monies received as donations | \$13,647.44 |
| Interest received on donations..... | \$166.97 |
| <i>Total Revenues</i> | <i>\$13,786.97</i> |

2. Expenses

| | |
|--|-------------------|
| Purchase of medications for overseas distribution | \$1,207.50 |
| Sponsorship of overseas meetings: Hanoi, Vietnam | \$1,000.00 |
| Sponsorship of travel to overseas meetings: Hanoi, Vietnam | \$500.00 |
| Translation expenses: Vietnamese | \$640.00 |
| <i>Total Expenses</i> | <i>\$3,347.50</i> |

3. Balance at End of Year

\$10,439.47

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 |
|---|-------------------------------|--------------------|----------------------------------|
| CLAN logo design, services & printing | Mal Salmon | \$3,000.00 | Advertising & promotion |
| Website services | Neil Jansons, Fred Shu | \$3,000.00 | Advertising & promotion |
| Printing, stationary & e-mail | Individuals | \$850.00 | Printing & stationary |
| Printing, discount on purchase | Kwik-Kopy (Auburn) | \$250.00 | Printing & stationary |
| Medications: Donation to Vietnam | Alphapharm | \$4,300.00 | Materials purchases: Medications |
| Medications: Donation to Vietnam | Bristol-Myers Squibb | \$1,350.00 | Materials purchases: Medications |
| Medications: Discount on purchase to Philippines | Alphapharm | \$350.00 | Materials purchases: Medications |
| MedicAlert bracelets (300) for overseas clients | MedicAlert | \$16,500.00 | Materials purchases: Other |
| CAH Booklets | Serono Australia | \$300.00 | Printing & stationary |
| Provision of patient management templates | Childrens' Hospital, Westmead | N/A | Printing & stationary |
| Travel: Airfares & accommodation to Vietnam & Philippines | Individuals | \$4,000.00 | Travel |
| Estimated Total | | \$20,800.00 | |

Notes: Volunteers have contributed hundreds of hours of support to CLAN. A special thanks to Don and Caz for baby-sitting!

The Price of Freedom



All children with CAH deserve the freedom to live their life the way they choose. Good health is an essential pre-requisite of such freedom, but unfortunately for many children of the world, the price of this is beyond their means. CLAN is in the privileged position of being able to help families and patients meet this cost, with the ultimate aim of freeing people of the burden that CAH too often becomes in resource-poor countries. As a result, we take fiscal responsibility very seriously.

For security and transparency, all donations to CLAN are handled by staff at RCHI, with official tax invoices issued to donors. Whilst CLAN enjoys an element of independence, in that it is able to prioritise where monies are spent, all expenditures are monitored by the RCH Foundation, and CLAN liaises at regular intervals with RCHI staff to discuss spending plans.



When deciding where monies are to be used, CLAN holds to the primacy of affordable access to essential medications as a platform for change. We are fortunate not only that hydrocortisone and fludrocortisone are reasonably inexpensive, but also that two key Australian pharmaceutical companies are exceptionally co-operative in facilitating our access to these drugs.



Once affordable access to medication has been achieved, CLAN then shifts attention to finding sustainable, affordable, culturally sound solutions to optimization of medical treatment and the encouragement of local CAH Support Groups. Educational activities are also a high priority to CLAN given our firm belief that "knowledge is power".

In 2006, CLAN will endeavour not only to maintain current commitments, but also to strive for new opportunities to help CAH families in resource-poor countries achieve the freedom they deserve.

An excerpt from a letter to CLAN from an Australian adult with CAH:

"Thank you for what you have achieved in 2005 for families with CAH... I never stopped taking my meds because the side effects of not having them was worse than anything I could imagine. I can't even begin to imagine how these children cope with the emotional turmoil of actually living with the side effects of having limited meds. You have helped to lift that pain. On behalf of all the children who now have hydrocortisone and fludrocortisone, thank you!"



Sponsors and Donors

Thank you to our generous donors and sponsors who have enabled CLAN to aim even higher!

Sponsors



Be impressive.

KWIK KOPY (Auburn)

142 Parramatta Road
Auburn NSW 2144

☎ 02 9748 1543

print@auburn.kwikkopy.com.au

www.auburn.kwikkopy.com.au



BRISTOL-MYERS SQUIBB AUSTRALIA

556 Princes Highway
Noble Park North VIC 3174

☎ 03 9213 4000

australc@meaumsg01.net.bms.com

www.bmsa.com.au



EXXO HOME LOANS

Suite 330, Level 3
1 Queens Road
Melbourne VIC 3004

☎ 1300 884 195

www.exxoloans.com.au



SERONO AUSTRALIA PTY LTD

Unit 3-4, 25 Frenchs Forest Road East
Frenchs Forest NSW 2086

☎ 02 8977 4100

www.serono.com.au



MEDICALERT

Level 2, 216 Greenhill Road
Eastwood SA 5063

☎ 1800 882 222

medic@medicalert.com.au

www.medicalert.com.au



ALPHAPHARM

Chase Building 2
Wentworth Park Road
Glebe NSW 2037

☎ 02 9298 3999

www.alphapharm.com.au

Donors

C & R Armstrong

M & N Salmon

N & R Jansons

M Konheiser

L & B Batchelor

Mrs P Armstrong

Miss E Batchelor

V & R Wiebe

B K & C Sinclair

Ms Margaret Caldecott

Misses A & H Ewens

Miss J Johnson

Mr A J Steel

Mr H Sondergaard

Ms C Henderson

P & G Scott

Any Donation to CLAN will be Joyfully Accepted!

Please contact: Helen Crawford
Business Development Manager
RCH International
Royal Children's Hospital
Flemington Road
Parkville VIC 3052
Australia
☎ 03 9345 5037

CLAN has also Developed a Couple of Fundraising Activities...



We automatically receive a percentage of profits every time products are purchased from the above two organisations when following the links on the CLAN web site.