

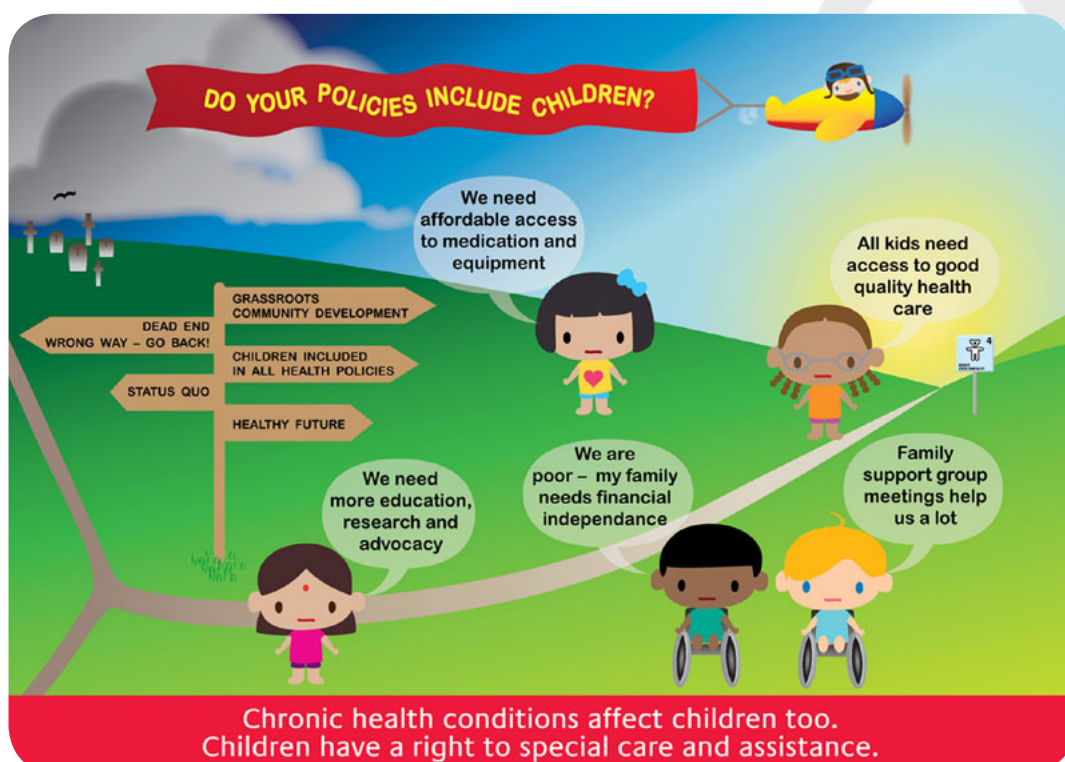
Clan Annual Report

JULY 2010 – JUNE 2011



Contents

About CLAN	1
President's Report	2
CLAN Office Bearers	3
CLAN Engages with UNDPI/NGO	4
NCDs, Children and Adolescents	5
UN Civil Society Interactive Hearing	6
CLAN's Framework for Action?	7
CAH CLAN	8
Diabetes CLAN	10
Autism CLAN	12
CLAN Partners in Action	
Grassroots Casestudy One	14
Grassroots Casestudy Two	15
CLAN Financials	16
CLAN Thanks You	17



About CLAN

Why does CLAN exist?

- Globally, chronic health conditions are a major cause of preventable disability and death.
- It is estimated that by 2015 there will be 1.2 billion children ages five to 14 living with a significant chronic health condition. Perinatal conditions, congenital abnormalities, measles and asthma are four of the 25 most common conditions associated with all Disability-Adjusted Life Years (DALYs) lost worldwide. Each year an estimated 7.9 million children are born with a serious birth defect, or genetic condition (there are more than 7,000 such conditions).
- To date there has been no specific forum at WHO or UNICEF that focuses on chronic health conditions in children. International chronic disease discourse has traditionally focused on adult lifestyle diseases. There is a lack of data relating to chronic health conditions in children, with statistics in WHO reports based on 'all ages', or 30 years plus. There are no policies to guide countries in the management of chronic disease in children. ✨

What is CLAN?

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

CLAN's Vision

- Our vision is that all children living with chronic health conditions in resource-poor settings of the world will enjoy a quality of life equivalent to that of their neighbours' children in higher-income countries. ✨

CLAN's Mission

- To maximise the quality of life for children and their families who are living with chronic health conditions in resource-poor settings of the world. ✨

What is CLAN doing to help children with special health needs?

- CLAN identifies a group of children with the same chronic health condition as a distinct community, then supports development through multi-sectoral partnerships at local, national and international levels to drive community priorities.

CLAN's strategic framework for action rests on five pillars:

1. Affordable access to medicine and equipment.
2. Education (of children, families, health professionals, policy makers, national and international communities), research and advocacy.
3. Optimisation of medical management (holistic care; primary, secondary and tertiary prevention).
4. Encouragement of family support groups.
5. Reducing poverty and promoting financial independence.

At all times the community of children remains the central focus. This ensures the children's voices are heard and enables a range of diverse and multi-sectoral stakeholders to unify around a common goal.

CLAN's community development approach ensures local ownership and genuine involvement in evaluation and planning. It has proven sustainable, effective and worthwhile in helping the world's poorest and most vulnerable children and families. ✨

Accountabilities

- On 27 May 2011, CLAN was formally accepted as a signatory to the Australian Council for International Development (ACFID) Code of Conduct. We have joined 123 other Australian organisations committed to improving international development outcomes and increasing stakeholder trust through enhanced transparency and accountability. ✨



President's Report

Dr Kate Armstrong



As a medical practitioner, public health enthusiast and mother of a child with a chronic health condition, Kate brings a broad knowledge base to her role as President of CLAN, which she founded in 2004.

Graduating from medical school in 1993, Kate has since worked in a variety of clinical and public health roles, and is currently completing her Doctorate of Public Health.

As CLAN pauses to reflect on another busy year that's been, it is encouraging to remember the words of Martin Luther King when he said:

"Our lives begin to end the day we become silent about things that matter."

Since 2004 CLAN has been anything but silent, committing instead to an extremely important humanitarian imperative, redressing the inequitable burden of morbidity and mortality experienced by children (and their families) who are living with chronic health conditions in resource-poor countries of the world.

In this regard, CLAN is surely living life to the full! We have had the incredible honour of sharing the journey with an inspirational network of partners, friends and colleagues, and experienced the thrill of witnessing real change for the communities of children we all focus our energies towards. Together we are finding the best ways to communicate the voices of the children and families we partner with at a grassroots level to the ears, eyes, hearts and minds of those in positions of power. Indeed, it is always rewarding when we can report back to the many families we work with in the Asia Pacific region that their stories are genuinely being heard, and that the plight of their precious loved ones really matters to the world.

If there has been one key learning for CLAN over the years it has been to cherish diversity. A particular strength of CLAN is our *Strategic Framework for Action* (please see page 7), and the ability this gives us as an organisation to unite a tremendous variety of people and skill-sets around the common goal of strengthening and developing the communities of children and families we partner with.

To the artists, musicians, sportsmen and women, bushwalkers, lawyers, health professionals, business people, philanthropists, fellow-NGOs, government officials, students and others who have joined us on this journey, we would like to sincerely thank you for all you have contributed to the well-being of the children of our region and our world. Together, we can make a difference. In fact, we are making a difference.

And as one noisy, busy collective that continually strives for the health of future generations, we can take comfort in the knowledge that this is what living life is all about.

Yours sincerely

Kate Armstrong



CLAN Office Bearers



Vice President – Kelly Leight Esq

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

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



Treasurer – Heidi Armstrong

Heidi Armstrong is the Treasurer of CLAN and is a qualified legal practitioner. Heidi no longer practices law, instead she runs her own mortgage management business State Custodians Mortgage Company. In this role Heidi directs the business activities of providing residential home loans to borrowers Australia wide. Heidi is a full member of the Mortgage & Finance Association of Australia and as the director of State Custodians, she has had to pass rigorous background checks including police, credit, audit and business reference checks to operate as a mortgage manager. Heidi uses her skills in running a business to assist CLAN in managing its financial affairs. ✨



Secretary – Cath Cole

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

Inspired by the work of CLAN, Cath has been the Secretary for CLAN since 2007. This reporting year, Cath has been overawed by the willingness of people to get involved and help out. Every little bit helps. Cath is very proud of CLAN's first major fundraising event, which has enabled CLAN to translate intent into action. ✨



Public Officer – Valerie Foley

Valerie Foley is the mother of a child with autism and the author of The Autism Experience - international perspectives on autism parenting. When she's not working on awareness raising and advocacy projects in the local autism community, she writes children's television programs.

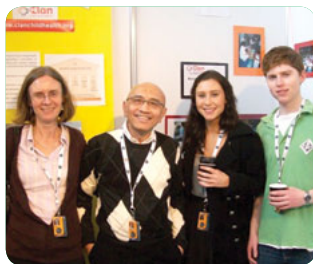
Working with Autism CLAN has been nothing short of a privilege for Valerie, and the highlights have included the Vietnamese recording of Through My Eyes, witnessing the growing acceptance and awareness of autism in Vietnam and seeing Australian peak autism bodies recognise and support CLAN's initiatives. ✨

CLAN Engages with UNDP/NGO

The 63rd UNDP/NGO Conference



Dr Aman Pulungan, Mr Shan Ali, Assoc Prof Maria Craig and Dr Kate Armstrong outside CLAN's Exhibit at the UNDP/NGO Conference in Melbourne, September 2010.



Dr Sue Ditchfield, Dr Aman Pulungan, Laura Healy, Chris Healy at the CLAN Exhibit.

- The 63rd United Nations Department of Public Information / Non-Government Organisation (UNDP/NGO) Conference "Advance Global Health – Achieve the MDGs" was held in Melbourne, Australia in September 2010. This was a fantastic opportunity to raise awareness of the issues facing all children living with any long-term health condition in resource-poor countries, as the global community seeks to achieve the Millenium Development Goals (MDGs) by 2015.

Moderated by Dr Kate Armstrong, CLAN hosted an Exhibit and Workshop at the conference. The Workshop focused on the need for a grassroots, community development approach to fulfilling the rights of children with chronic health conditions in resource-poor countries to health and life. CLAN is very grateful to the brilliant team who helped to make our Conference Workshop possible:

- Prof Garry Warne (Royal Children's Hospital International) spoke on the need for affordable access to essential medicines and equipment
- Assoc Prof Maria Craig (Children's Hospital Westmead and the Australasian Paediatric Endocrinology Group) spoke on the power and importance of education, research and advocacy
- Dr Aman Pulungan (Dr Cipto Mangunkusumo Hospital, Jakarta; the Indonesian Pediatric Society's Endocrinology Chapter and the Asia Pacific Pediatric Endocrinology Society) spoke on the situation for children with chronic conditions in Indonesia
- Mr Shan Ali (Chair of Grameen Foundation Australia) spoke of Grameen's views on the links between health and poverty, and challenges facing families of children who have serious health problems.

Perhaps the best overall outcome from this conference was the meaningful inclusion of children within the final Declaration. The entire Declaration is available online, but some particularly encouraging excerpts are:

- The call to "Actively support, encourage and resource community voices to be heard through active representation in program planning, implementation and evaluation; always including representation of women and men, children, youth and older persons, indigenous peoples, the disabled and marginalized groups"
- Acknowledgement that "it is unacceptable that so many children and adults in low income countries continue to suffer preventable illness, disability and premature deaths each year. The world knows how to prevent and treat most of the causes and has shown that well-focused efforts can significantly reduce levels of suffering".

CLAN would like to sincerely thank ADRA International for sponsoring our Workshop and Dr Sue Ditchfield, Chris and Laura Healy for their fantastic efforts with CLAN's Exhibit. ✨

Committee Member Profile: Amy Eussen



- Amy Eussen (pictured left) is an international public lawyer. Amy has worked in the Netherlands for close to four years and gained experience in human rights applications and advices and proceedings at international tribunals. Her passion is in the protection and promotion of human rights, especially children.

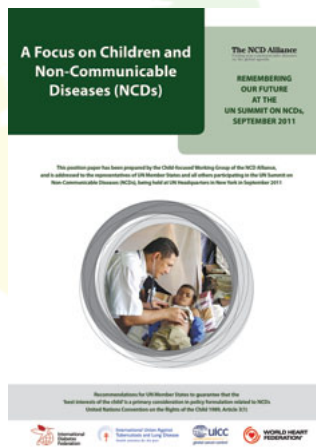
Amy began to work for CLAN at the end of 2009 as the UN Coordinator and Human Rights Advisor. Over the last 18 months, she has assisted CLAN in becoming more engaged with the UN and on the world stage.

Since January 2011, Amy has helped Dr Armstrong facilitate her role as Chair of the NCD Alliance Child-focused Working Group. Amy attended the UN Civil Society Interactive Hearing on NCDs in June 2011 and conferences around this time with the Global Health Conference and St Jude, Cure4kids. In the course of this work, the CLAN operated project 'NCD Child' was created to allow for increased involvement in lobbying and advocacy efforts related to child health issues. NCD Child has taken a human rights based approach to ensure that child health rights are considered in all policies and that our future is not forgotten. Amy is the project manager of NCD Child. ✨



NCDs, Children and Adolescents

Child-focused Working Group



- In late 2010, Dr Kate Armstrong, as President of CLAN, took on the role of Chair of the Child-focused Working Group of the NCD Alliance. Interest in the Working Group was extraordinarily high, and over time it became essential to find an effective way to communicate with such a fantastic network of people, all equally passionate about children and their representation within the emerging Non-Communicable Disease (NCD) discourse. Essential to the success of the Child-focused Working Group of the NCD Alliance was its ability to step beyond disease-specific self-interest and contribute in a meaningful way to the desperate and urgent need to integrate children within the global NCD discourse. The Group enjoyed enormous interest and support from every possible corner. An introduction to the broader NCD Alliance membership during a Common Interest Group Meeting in January 2011 resulted in a barrage of emails with emphatic requests to be involved in all activities of the group. An inclusive and consultative approach to the conduct of the Working Group meant that membership grew rapidly (with a range of NCDs represented), and the quality of interested participants was nothing short of world class.

As one of the youngest Working Groups of the NCD Alliance and with less than four months to go before the UN Summit on NCDs, the Child-focused Working Group recognised the need to set aggressive goals and hit the ground running. The initial imperative was to establish the terms of reference for the new group and develop as a matter of urgency a policy brief on children and NCDs that could be used as an advocacy tool by the NCD Alliance. Again, an inclusive and collaborative approach was adopted in the development of this brief, and it was first made available online <<http://www.ncdalliance.org/children>> in April 2011. A published version of the brief was formally launched at the First Global Ministerial Conference on Healthy Lifestyles and Non-Communicable Disease Control in Moscow and further distributed at the Commonwealth Partners meeting and World Health Assembly in Geneva in May 2011.

A direct outcome of the policy brief development process was the belief by many members of the Child-focused Working Group that an all-encompassing comprehensive document on children and NCDs was needed. The policy brief was acknowledged to be an effective starting point, but each disease-specific group felt that they had more to share with – and learn from – their counterparts. A call was made to the Working Group in February for any members who might be interested in collaborating to formulate this document, and an overwhelming response was received. The document (A Focus on Children and Non-Communicable Diseases, pictured left) was launched and distributed at the Global Health Council (GHC) Conference in Washington on 13 June 2011 to coincide with International Children’s Day. The document, with its strong focus on prevention (primary, secondary, and tertiary), supports 20 “Recommendations for Action” to UN member states that will drive sustainable change and improvements in global child health with regard to NCDs. ✨

Global Health Council Conference



- CLAN representatives attended the Global Health Council Conference in Washington “Securing a Healthier Future in a Changing World”, having convened a panel entitled “Don't forget our future! Global approaches to NCDs and children”. The purpose of the panel was to draw attention to the UN High-Level Meeting on NCDs in September 2011 and to further promote a strong platform from which to advocate for the integration of children within the NCD discourse.

Sincere thanks to Assoc Prof Felicia Knaul (Harvard Global Equity Initiative), Dr Sara Stulac and Assistant Professor Gene Bukhman (of Partners in Health), Dr Kate Armstrong (CLAN) and Kelly Leight Esq (representing Prof Brad Therrell, Director, National Newborn Screening and Genetics Resource Center, USA) for their fantastic contributions. The panel brought together a range of experiences from different parts of the world to highlight the relevance of children to the NCD discourse; effective approaches that have been taken to redress global inequities; and the value of scaling up efforts so far (with particular focus on prevention).

The time in Washington once again proved a fantastic opportunity to network and CLAN was invited to attend the Luxembourg Ambassador’s residence for a reception with the NCD Alliance (pictured left). ✨

UN Civil Society Interactive Hearing

UN Civil Society Meeting



Pictured L-R: Jeff Meer, Amy Eussen and Dr Kate Armstrong at the UN General Assembly

- In June 2011, CLAN representatives took part in the UN Civil Society Interactive Hearing on Non-Communicable Diseases (NCDs), held in the General Assembly of the United Nations HQ. Dr Kate Armstrong was invited by the WHO Taskforce organising the High-Level Meeting on NCDs to address the meeting on "Children, Adolescents and NCDs". Copied below is a transcript of the speech Kate gave that day.

"I speak today as President and Founder of the non-profit NGO CLAN (Caring & Living as Neighbours) and have been working as the Chair of the Child-focused Working Group of the NCD Alliance. I am here to share the voices of the millions of children and adolescents around the world who are living with chronic health conditions here and now.

Non-Communicable Diseases (NCDs) are at the forefront of our minds as we approach the UN Summit in September 2011, but it is important to note that any chronic health condition – be it asthma, diabetes, cancer, heart disease, autism, epilepsy, endemic NCDs, HIV/AIDS or TB – has the potential to destroy our children if not prevented, diagnosed or managed appropriately.

Member states have long acknowledged that children as a vulnerable group are entitled to special care and assistance. In 1989 the international community made a clear commitment to the rights of children with the adoption of the United Nations Convention on the Rights of the Child which guaranteed an all encompassing set of human rights, including the right to the enjoyment of the highest attainable standard of health. The near universal ratification of this Child focused Convention makes a rights based approach central to NCD discourse and policies. Yet despite this widely ratified convention, the reality is that enormous global inequities exist for children living with chronic health conditions in low and middle-income countries.

The thousands of families CLAN works with throughout Asia provide valuable lessons on the power of a community based approach to working together to effect sustainable change.

When we identify children living with the same chronic health condition as members of a distinct non-geographically based community, we empower them to engage with a broad range of multisectoral stakeholders to unite to achieve 5 key deliverables that families have identified:

1. Affordable access to essential medicine and equipment
2. Education, Research and Advocacy
3. Optimal medical management (primary, secondary and tertiary prevention and a holistic approach to health)
4. Family support group networks and
5. A pathway to financial independence and freedom from poverty.

For member states and civil society needing proof of the importance of including children in all NCD policies, I draw your attention to the evidence-based document produced by the Child-focused Working Group of the NCD Alliance. This policy paper clearly reflects that children are the cornerstone to the prevention of the NCD epidemic we face.

On behalf of children and families all around the world I call on member states of the United Nations, UN agencies including UNICEF and the private sector alongside civil society to specifically address and include children in all NCD policies as a matter of justice, not charity.

We must not forget our future." ✨

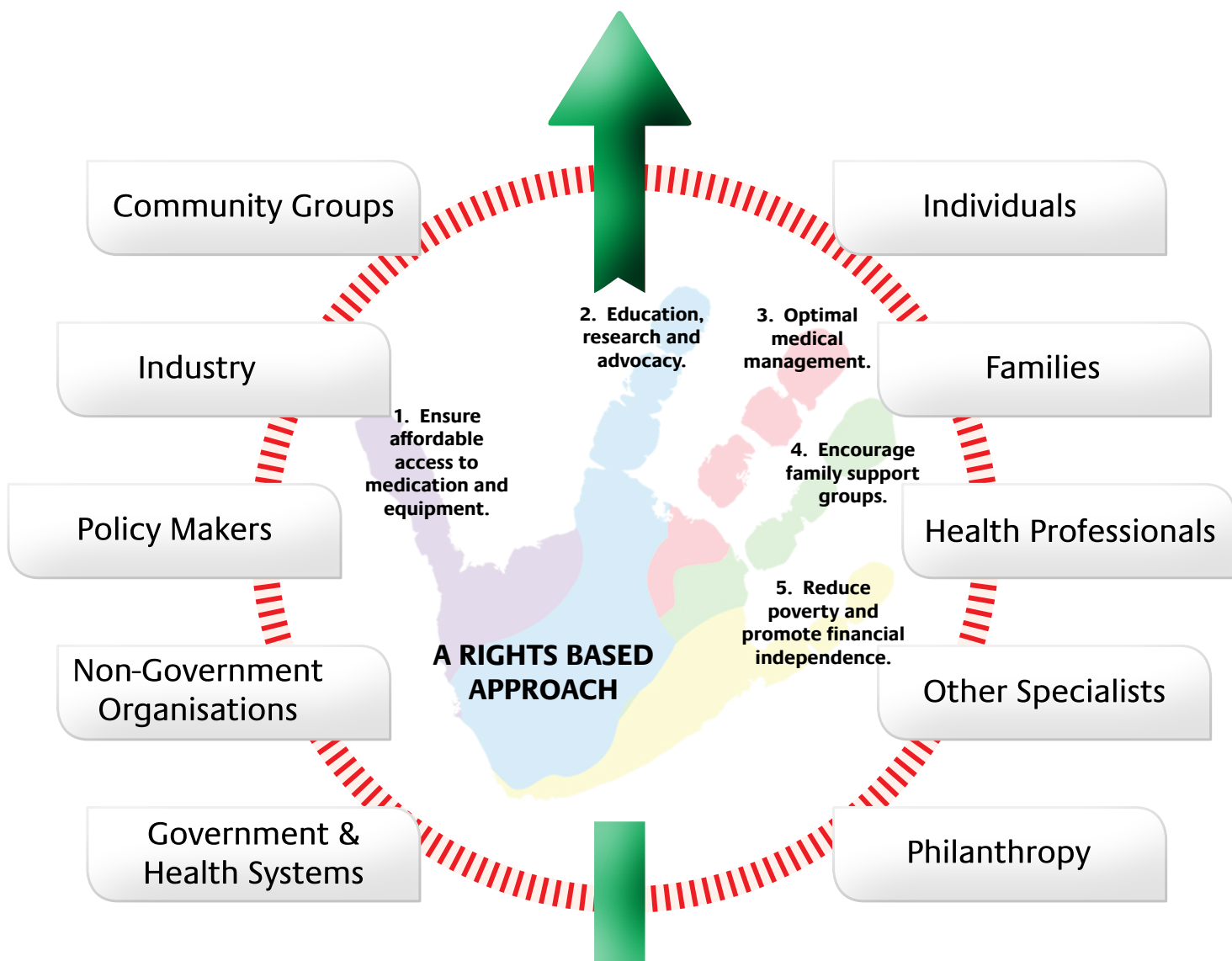


Dr Kate Armstrong presents "Don't Forget Our Future" at the UN Civil Society Meeting on NCDs held in the General Assembly of the United Nations HQ.

CLAN's Framework for Action

Our mission is to maximise quality of life for children (and their families) who are living with chronic health conditions in resource-poor countries of the world

HIGHEST QUALITY OF LIFE



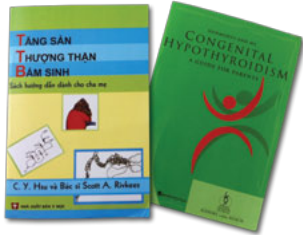
A community of children, Hanoi 2007. All children in this photo have the same chronic health condition and their families meet regularly for support.

CAH CLAN

CLAN's First Major Fundraising Event Pays for Educational Material

- Forty two walkers raised an amazing \$21,050.00 for CLAN walking across the 6ft track in the Blue Mountains, New South Wales on the weekend of 18 and 19 September 2010.

With a nine strong support crew, our walkers trekked for 40km over two days in pristine bush land in support of CLAN. With the money raised we translated 'Congenital Adrenal Hyperplasia A Parents' Guide' by C Y Hsu and Dr Scott A Rivkees into Vietnamese and are translating other endocrine booklets into different languages (pictured left).



Two thousand copies of the CAH book were printed and distributed at no cost to all families at club meetings in Vietnam in July 2011.

CLAN is passionate about the importance of enabling families of children with chronic health conditions to access quality educational resources in their own languages, and so moving forward are also collaborating with partners in Australia and in Vietnam on two books on autism and early discussions are underway for books on diabetes and CAH in Bahasa Indonesian. These achievements would not be possible without the fund raising efforts of the 6ft Trackers.

Our sincere thanks to all our walkers for joining the CLAN family and helping us on the journey. Heartfelt thanks to Stephen McClure, a dear friend of CLAN, mastermind behind this fund raising event. It would not have been as successful, or made possible, if not for his efforts. Special thanks also to Peter Cole, Trish McClure, Mark Wallis, Darryl and Mandy Herbert and Dave Hansen whose help was invaluable. ✿



6ft Track Walk Organisers (L-R) Cath Cole and Steve McClure.



Above: Walkers and support crew for the 6ft Track walk 18-19 September 2010.

IKAHAK Enterprise Development Program Evaluation

Summary from report prepared by CLAN volunteer, Jordan Filko

- For the past two years CLAN has been reporting on the CLAN-IKAHAK Enterprise Development Program implemented in Surabaya Indonesia to provide families in the CAH support group with a sustainable, self-generated source of income. The program provides interest free loans and support including mentoring, business training, financial literacy and health education.

“This year CLAN evaluated the program with input from Dr Kate Armstrong, Dr Muhammad Faizi of IKAHAK and Ms. Lenny Kristiana, a keen participant and coordinator of the program.

Unique to this program was that the selection of participants for the microfinance project. Typical micro-finance projects target geographically based communities, whereas the IKAHAK project identified families unified by the shared experience of caring for a child with CAH. The program started with a loan to four CAH families of US\$400 each. After two rounds of loans a total of \$3,640 has been loaned and repaid in full.

An evaluation at the completion of two loan rounds found that, as a direct result of families’ participation, 33% of eligible children with CAH were able to access critical surgeries with project families and doctors confirming that this is a clear benefit. In addition, the children’s general health was reported to have improved through enhanced access to regular medical care. The success of the project was also measured by families’ financial situations. In the EDP, not only were repayment rates 100% but borrowers took second round loans, requested larger loan amounts and generated interest among other IKAHAK members in joining the EDP.

The main strengths of the project were found to be its focus on social returns for participants. Families brought together by the EDP found solace in their shared experience. The focused and well-thought out support structures for participants and the unique bond shared by borrowers of experience with the same disease was critical to success.

Challenges to address going forward centre primarily on documentation and institutionalisation of practices to enable scalability and replication. Opportunities include integration with local microfinance organisations as well as tools of the broader microfinance industry, inclusion of a mobile banking component and potential partnerships with organisations of families living with CAH in developed countries.

Perhaps the most exciting potential for the future of the EDP is expansion to promote greater support for improved income generating capacity of families and individuals living with chronic diseases in developing countries across the world, an enormous population that is currently underserved by both the development, health and microfinance industries.” ❖

CAH Clubs in Vietnam



Above: Staff at the National Hospital of Pediatrics in Hanoi teach families how to give life saving emergency Hydrocortisone injections

- In September 2010, CAH Club meetings were held at the three largest children’s hospitals in Vietnam with around 400 families attending. There were many indications that the CAH community in Vietnam is benefiting from the combined efforts of the many partners CLAN works with. For the first time CLAN no longer had to import Florinef or Hydrocortisone tablets as they are now available locally. Educational talks on genetics highlighted advances in this field of medicine in Vietnam and training sessions for families mean parents are prepared to give life saving emergency Hydrocortisone injections.

A strong presence of the Vietnamese media meant the CAH Club featured on O2TV (a national station) for the first time. A research project on the height and weight of children with CAH will help health professionals in Vietnam track future achievements and improvements in health outcomes. CAH Club Executives have been very active in Vietnam, helping families connect and support one another.

We wish the CAH community in Vietnam every success for the future and have every confidence they will continue to go from strength to strength. ❖

Diabetes CLAN

Global Solutions for Children with Diabetes

- Diabetes is a non communicable disease (NCD) and as such is one of four conditions identified for focus at the UN Summit on NCDs to be held in New York in September 2011. CLAN has embraced the opportunity to raise the voices of children who are living with Diabetes within our advocacy efforts leading up to the UN Summit. We are grateful to the many partners we have worked with over the years such as the IDF's Life for a Child (LFAC), International Insulin Foundation (IIF) and GPED (Global Paediatric Endocrinology and Diabetes) for their collaborative efforts in this regard. ✨

New Relationship with Life for a Child



- In late 2010, the International Diabetes Federation (IDF) Life for a Child (LFAC) Program and CLAN undertook a Memorandum of Understanding (MOU) with Children's Hospital 2 (CH2), HCMC Vietnam, with the goal of maximizing the quality of life for children with Diabetes who attend this major tertiary paediatric hospital for care.

Since undertaking this agreement LFAC has generously supported the purchase of an HbA1c machine and test strips so that children can now have these important blood tests performed on site when they present for check ups. This saves families significant money and time and has been a great step forward for the Diabetes community at CH2. Betacheck strips are also being made available to families to help reduce the cost of regular blood glucose monitoring,

CH2 is now collating important data on their Diabetes patients and will use these to guide future efforts for the children. ✨

Diabetes Research

- At the Diabetes Club meetings held in Vietnam in September to October 2010, families were again offered the opportunity to receive free HbA1c testing for their children. This important blood test (which is an invaluable marker of longer term blood glucose levels) is often not affordable for many families. Results were made available to families on the day and educational sessions at the club meetings helped families to interpret what these numbers meant. Collation of the data is also enabling longitudinal research on Diabetes in Vietnam and it is hoped that future publications will continue to highlight the many opportunities that still exist to support these children to enjoy the highest quality of life possible. ✨



Sponsorship of Fellows to attend APPES in September to October 2010

- With the ongoing development of Paediatric Endocrinology as a medical speciality in its own right in Vietnam, there is an increasing interest amongst young doctors in attending the regional Asia Pacific Paediatric Endocrinology Society (APPES) Scientific Training sessions for Fellows. In 2010, CLAN was pleased to indirectly sponsor Drs Khanh Phuong Nguyen and Huyen Tran Thi to attend the APPES training. In return for attendance these talented health professionals undertook the translation of the Merck Serono booklet on Congenital Hypothyroidism (CH) and CLAN is confident that this will become a valuable resource for families and health professionals in Vietnam particularly as the government looks to expand Newborn Screening for CH in the country. ✨



Fish Walks the Dog

- Meet Fish: devoted biker, God's Squad member, and father of seven. Fish was never one to give much thought to diet or exercise until diagnosed with Type 2 Diabetes some years ago. Even then he didn't take it seriously. But for the last year and a half Fish has been making a big effort to get his condition under control and believes the big secret of his success has been long walks with his dog, five-year-old Zeke.

In May 2011, Fish and Zeke set off on an 873km journey from Sydney to Melbourne to raise awareness of Diabetes and funds for CLAN's activities to support children with endocrine conditions. Fish and Zeke's epic walk tied in fantastically with CLAN's efforts to raise awareness of diabetes and other non communicable diseases as they relate to children in United Nations forums.



Congratulations Fish on an incredible achievement. Sincere thanks to all those that helped him along the way. Special thanks to State Custodians Mortgage Company for donating \$100 to Fish for each new home loan received during his walk. In total Fish raised over \$15,000 enabling CLAN's support of Diabetes Club meetings to continue in 2011 and beyond. ✨

Diabetes Support Clubs in Vietnam

- In September – October 2010, Diabetes Club meetings were successfully conducted at the three major children's hospitals in Vietnam with around 150 children and their families attending. A highlight of the meetings was the observation by Assoc Prof Maria Craig that an unusually large number of small babies had been diagnosed with Type 1 Diabetes. Recent research from the UK suggests these babies might in fact have a condition known as Neonatal Diabetes, in which case they will no longer require insulin treatment and instead receive tablet medication. Blood samples were collected from the babies for free genetic analysis in the UK and the future for these children looks bright.

As in past years, free HbA1c blood tests given to each child to help monitor their Diabetes care. Because this blood test is beyond the means of many families, parents were grateful for the chance to have the test performed and also have the results explained to them in some detail. The data collected will also be used in ongoing research of Diabetes in Vietnam. Fiona Tran, medical student from Australia, gave a great talk to families on the results of the 2009 HbA1c survey and encouraged families to keep doing their best for the children. Fiona acknowledged 'resilience' as a key feature of Vietnamese culture and encouraged families to stay strong.

Educational talks were a feature of all the meetings with Nuala Harkin, Assoc Professor Maria Craig and local health professionals providing important information to families. All families now have copies of the purple Diabetes book – Caring for Children and Adolescents with Diabetes – which is now also available on line. Excitingly, many young people living with Diabetes and also parents spoke at the meetings and families took great encouragement from one another.

Diabetes remains a challenging condition for children and families in Vietnam – particularly those from poor rural areas. CLAN is especially grateful to Life for a Child and other NGOs like ACCV who work hard to help the children enjoy the highest quality of life possible. ✨



Autism CLAN

Hoc Mai Training



- CLAN is grateful to the Hoc Mai Foundation for their generous sponsorship for three Autism health professionals from CH1 HCMC Vietnam to travel to Australia as a multi disciplinary team, and network with some of the leading Autism organisations in New South Wales and Victoria. Dr Trang (a paediatrician), Mrs Tra (a psychologist) and Mr Quyen (a physical and speech therapist – pictured left) spent two months in Australia and had the opportunity to experience a wide range of Autism services that are available in this country.

The visiting staff had two main objectives for their visit. Firstly, to develop a tool kit of resources which they could then take back with them to Vietnam and share with colleagues and families. The second was to develop individual research action plans that they would then implement on their return. Mrs Tra's project on the use of PECS (Picture Exchange Communication System) resources looks to expand in future to a small research project and this is an exciting development for the Autism community.

We are excited that Dr Trang will be speaking about this project at the Asia Pacific Autism Conference (APAC) in Perth in September 2011. We hope this will continue to strengthen international links between Vietnamese and Australian Autism communities. Sincere thanks must go to the many Australian stakeholders who were actively involved in this project. Without their generous support the entire project could not have gone ahead. ❖

Early Childhood Intervention Conference in Malaysia, December 2010

- Sincere thanks to John Forster of Early Childhood Intervention Australia and Trish Hanna of Learning Links Australia for joining CLAN in supporting Dr Trang (paediatrician at Children's Hospital1) and Mr Giao, physical therapist, also of CH1, to attend the third National Early Childhood Intervention Conference (NECIC) from 2nd to 4th December 2010 in Malaysia. The theme of the conference was Early Childhood Care and Education – Working in Partnership Towards Inclusion. The staff from Children's Hospital 1 enjoyed the conference very much. ❖

"We learned how important it is to have a multidisciplinary team that co-ordinates efforts between the Ministries of Health and Education; grassroots efforts for women, children and community development; and larger international associations such as UNICEF and governments. NGOs have a significant function in community development!"

Royal Children's Hospital Int'l (RCHI) Project



Nephrotic Syndrome team from NHP in a PFCC focus group.

- In 2011, CLAN partnered with Royal Children's Hospital International (RCHI) and the National Hospital of Pediatrics (NHP) in Hanoi on a project to promote Patient and Family Centred Care (PFCC) at NHP.

PFCC is recognised internationally as central to achieving world class standards in health care and aligns with the World Health Organisation's focus on People Centred Health Care. The core principles of PFCC are dignity and respect; information sharing; participation and collaboration and NHP was keen to explore opportunities to promote these concepts within the context of existing and emerging family support groups.

Families and health professionals from Autism, CAH, Diabetes, Epilepsy and Thalassaemia Clubs met and discussed community development approaches to building local capacity to maximise quality of life for the children and enhance patient and family centred care at the hospital. An additional positive outcome was the presentation of this project at the internationally recognised Consumers Reforming Healthcare Conference in Melbourne in July 2011 by Dr Hung of NHP. ❖



The PFCC project team.



Autism team from NHP in a PFCC focus group.

Supporting the Autism Community in Vietnam

- CLAN was proud to highlight the amazing efforts of the Hanoi Autism community again this year. On 2 April 2011 this community successfully held their annual walk through the streets of Hanoi raising \$US18,000. CLAN is thrilled that Valery Foley's song 'Through My Eyes' continues to be used by the community to promote their work and raise awareness in Vietnam of what life is like for children who are living with Autism. ✨



Da Lat Project

CLAN and the Mai Anh Special School



- The Mai Anh Special School in Da Lat is run by nuns in an under-resourced setting. The school provides care for approximately 40 children of local families who are unable to adequately meet the special needs requirements of their children, 10 of who have Autism Spectrum Disorder (ASD). Despite limited resources, staff are keen to provide quality care, and in 2008 approached CLAN with a request for training in the field of Autism and hearing impairment.

After undertaking a capacity building training project for staff working in the field of ASD at Children's Hospital 1 in HCMC in 2010 (with thanks to funding from Hoc Mai Foundation), CLAN was keen to collaborate with partners in Ho Chi Minh City to trial an action research training project in a rural/remote setting to meet the needs of children with Autism there.

In collaboration with Children's Hospital 1 (CH1) in Ho Chi Minh City, and Gia Dinh Special School, CLAN funded an information and expertise sharing process with a four-day workshop at Mai Anh School from 20 to 23 January 2011.

Early consultation established clear learning objectives and evaluation measures for the project. The total cost of the project to CLAN was A\$800.

Medical professionals worked with families, caregivers and teachers to further assess the needs of the children, families and staff, and initiate training on topics including:

- characteristics and needs of children with different psychological disorders
- psychological support for parents and educators
- speech and language therapy
- physical therapy
- completing PEP 3 and independent education programs
- treating, teaching and learning
- music and basic occupational therapy.

As a result of the workshop medical, developmental and socio-economic assessments of 10 children with ASD were completed. Current teaching practices were reviewed and recommendations made. The principles of the TEACHH Program were shared, and ongoing information sharing processes between the school and the hospital were established.

The staff at Mai Anh will require ongoing support and regular supervision from CH1 and Gia Dinh School if they are to achieve continued and sustainable change. Following the success of the workshop, the staff of Mai Anh hope for more training on ways to provide psychological support to the educators and caregivers. Ongoing evaluation is planned, however, results so far indicate that this project offers a cost-effective, collaborative model for building capacity of grassroots organisations to support children and families living with ASD in remote and rural areas of Vietnam. ✨

(Pictured Left) Image 1: Dr Thanh, pedo-psychiatrist is sharing knowledge about diagnosis and treatment of autism with the educators in Mai Anh special school.

Image 2: Music therapy with Ms Khoai (front right in black/pink) and educators.

Image 3: Ms Khoai director of Gia Dinh special school, is discussing with educators about assessment of autistic child's development.

Image 4: Dr Thanh is sharing with parents about caring autistic children.

CLAN Partners in Action

Grassroots Casestudy One: National Institute of Child Health, Pakistan

**First Laron Meeting,
11 January 2011,
National Institute
of Child Health,
Karachi**

**An update from
Dr Yasir Khan**

Introduction:

Laron Syndrome or most commonly referred to as Growth Hormone Insensitivity (GHI) is a rare genetic illness which when properly diagnosed can be treated. Treatment cost can vary from USD 700-1400 or more per month per individual patient with duration of treatment lasting many years so children can achieve the highest quality of life possible.

Considering the economic inflation which presently at an estimated 25% in a country whose GNI per capita is US\$770 (UNICEF – 2006) the treatment for even well off families seems like a farfetched dream.

The National Institute of Child Health (NICH) in Karachi has 15 children diagnosed with Laron Syndrome registered in their outpatient department, and sadly only two patients are on treatment.

Under the leadership of Professor Jamal Raza, NICH and the families have united as a community, and strive towards action around the Five Pillars of CLAN so that all members of the community enjoy the best outcomes possible. A key focus will be ensuring funds are generated to arrange treatment for all GHI patients.

Important Outcomes of Efforts to Date:

1. All families now understand the disease, high cost of treatment and the complex procedure by which the drug has been made available in Pakistan.
2. The important contribution of Prof Ron Rosenfeld and Dr Vivian Hwa from Oregon Health and Science University in providing free genetic testing and their help in making treatment available for Pakistani patients was explained to the families.
3. All fund raising will be done under the banner of Atfaal Welfare Society (registered) and the National Institute of Child Health.
4. A special section on the Atfaal Welfare Society website will be designated totally for GHI which will firstly attempt to explain the disease in simple layman words and secondly will also contain precise instructions on how donations can be made for this cause.
5. All families will be assigned tasks based on their capabilities in short everyone will help pitch in for the cause.
6. Dr Yasir Naqi Khan will coordinate all fund raising activities and will help in arranging monthly meetings so progress can be followed up.
7. Professor Syed Jamal Raza and the full faculty of the endocrine ward will be available for meetings with donors.
8. General awareness materials will be made available so that more and more people become aware of the disease and the high cost of treatment.
9. All online resources (Facebook, e-marketing etc) will be used to target foreign donors.
10. USAID will also be approached with the help of our foreign partners.
11. All families have given their consent to use their photographs on the website plus for any printable materials that may be required for the campaign. ✨



Grassroots Casestudy Two: Supporting CAH and Diabetes Families in Indonesia

CLAN provides long term support for families in Indonesia

A summary of a paper presented by Dr Rara Purbasari

- Dr Rara Purbasari, in her paper Challenges in Management of Paediatric Congenital Adrenal Hyperplasia & Diabetes Mellitus in Indonesia highlighted the recent increase in children presenting with chronic endocrine conditions and the limited resources available locally to respond – particularly in rural and remote areas.

Dr Purbasari shared that until recently there had been no epidemiologic data available to communicate the status of chronic conditions in Indonesia's children. However, since the Indonesian Endocrinology Chapter of the Indonesian Paediatric Society collaborated with the World Diabetes Foundation in a project to increase awareness about Type 1 Diabetes (T1DM) management and Diabetic Ketoacidosis (DKA), many changes have been made. A national registry of children with T1DM has been implemented which has resulted in many children with Congenital Adrenal Hyperplasia (CAH) also being registered. Recent data from the registry reveals significant increases in the number of children with DM and CAH. At the beginning of the registry in May 2009, only 200 children were registered (40 with CAH and 160 with T1DM). In April 2011 there were 768 children registered (609 with T1DM, 29 with T2DM and 130 with CAH, demonstrating an alarming 300% increase in numbers in less than two years.

Despite this dramatic increase in the number of children with chronic endocrine, supporting facilities for paediatric endocrine management in Indonesia had not increased proportionally and existing facilities were mostly concentrated in urban areas. This means that medicines and/or medical supplies such as insulin, glucometer or glucotest strips are not equally available between islands, provinces, cities or even between different hospitals. The lack of readily available medicine was especially critical for children with CAH who are at risk of going into adrenal crisis without continuous hydrocortisone treatment. With neither oral nor intravenous hydrocortisone available in pharmacies in Indonesia this was an alarming and real concern. In addition, delays in accessing laboratory test results (often performed abroad), makes medical management both costly and time consuming.

Dr Purbasari recognises the important role that family organisations play role in supporting children with chronic conditions citing Keluarga dengan Anak penyandang Hiperplasia Adrenal Kongenital Indonesia (KAHAKI) as the first advocate for making CAH medications available in Indonesia. "Without outside support KAHAKI struggled to provide the appropriate medications. However, KAHAKI finally found assistance from the Caring & Living as Neighbors (CLAN) organisation." Dr Purbasari wrote that CLAN has been crucial in KAHAKI's efforts to improve conditions for Indonesian patients with CAH, specifically by donating education materials, implementing supporting programmes and most importantly assisting with the donation of medications through collaborative links with Alphapharm, manufacturers of hydrocortisone in Australia. Dr Purbasari writes, "Since 2008, CLAN and Alphapharm have given Indonesia the medications it so desperately needed, for free. This collaborative effort helped KAHAKI to maintain the crucial medicine supply available for all CAH children in Indonesia. Thank you so much to ALPHAPHARM and CLAN for their generosity to Indonesian children."



Both CLAN and Dr Purbasari promote community support and collaboration as "powerful tools to encourage healthcare providers and the government to pay more attention to our children's needs." Dr Purbasari expresses hope "that developing additional collaborations and deepening our involvement with existing partners will continue to improve the quality of life and health for children with chronic conditions in Indonesia." Dr Purbasari kindly acknowledges CLAN as "a great family organisation model that we can strive towards and with their help we have already gone far." ❀

CLAN Financials

Income and Expenditure Statement for the Year Ended 30 June 2011

CLAN

ABN 30 897 322 928

	2011 \$	2010 \$
INCOME		
Donations	70,971	17,321
Members' Subscriptions	685	682
RCHI Final Accounting	-	12,397
RHCI Support	-	3,000
Consulting	16,155	-
Interest Received	718	178
Other Income	80	-
Total Income	88,609	33,578
EXPENDITURE		
Accountancy and Audit	2,000	760
Bank Fees and Charges	127	30
Computers	390	-
Depreciation	2,487	-
Dues and Subscriptions	312	-
Insurance	-	1,388
Legal Fees	-	700
Printing, Postage and Stationery	7,198	866
RHCI Consultancy	2,400	-
RHCI Travel	-	3,000
Telephone	146	-
Travel, Accommodation and Conferences	12,139	1,423
Website	57	1,245
UN Travel	194	-
Vietnam Medication	5,140	322
Vietnam Training	1,921	800
Translation	2,269	-
Vietnam Hospitals	23,900	-
Vietnam Travel	4,490	-
Indonesia Training	939	1,100
Indonesia MicroFinance	-	2,285
Pakistan Training	3,830	-
Total Expenditure	69,939	13,919
NET PROFIT / LOSS FOR THE YEAR	18,670	19,659

From Independent Audit Report to Members of CLAN (Caring & Living As Neighbours) Incorporated, ABN 30 897 322 928

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

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

CLAN Thanks You

*CLAN could not operate without the generous collaborative efforts
and contributions of our wonderful partners and sponsors.*

*Thank you so much to everyone involved for your care and compassion for children
living with chronic health conditions in low-income settings.*

Change is possible when we all work together!

Alphapharm

<http://www.alphapharm.com.au>

Aspect Australia

<http://www.autismspectrum.org.au>

Atfaal Welfare Society

<http://www.atfaal.com.pk/clan.shtml>

Betachek

<http://www.betachek.com>

CARES Foundation

<http://www.caresfoundation.org>

**Children's Hospital 1 (CH1),
Hoi Chi Minh City**

**Children's Hospital 2 (CH2),
Hoi Chi Minh City**

Children's Hospital Westmead (CHW), Sydney

<http://www.chw.edu.au>

Diabetes NSW, Australia

<http://www.diabetesnsw.com.au>

Jordan Filko

Fish and Zeke

Grameen Foundation Australia (GFA)

<http://www.grameen.org.au>

Hoc Mai Foundation, Australia

<http://sydney.edu.au/medicine/hocmai/>

C Y Hsu

Indonesian Pediatric Endocrinology Group

Insulin For Life (IFL)

<http://www.insulinforlife.org>

Life for a Child

<http://www.lifeforachild.org>

Lifestart, Eastwood, NSW

<http://www.lifestart.org.au>

Steve McClure

National Hospital of Pediatrics, Hanoi

http://www.benhviennhitu.org.vn/intro_en.asp

National Institute of Child Health, Karachi

NCD Alliance

<http://www.ncdalliance.org>

Novo Nordisk

<http://www.novonordisk.com.au>

Peekaboo Creations

<http://www.peekaboo creations.com.au>

Philippines General Hospital, Manila

Dr Scott Rivkees

RMIT, Vietnam and Australia

<http://www.rmit.edu.au>

Royal Children's Hospital International (RCHI)

<http://www.rch.org.au/rchi>

Royal Children's Hospital (RCH), Melbourne

<http://www.rch.org.au>

Six Foot Trackers

Sozo volunteers

<http://www.sozonet.com/en/sozo-good/sozo-volunteer>

State Custodians Mortgage Company

<http://www.statecustodians.com.au>

Sticky J Jewelry

<http://www.stickyj.com>

Think Walsh Creative Solutions

<http://www.thinkwalsh.com>

Fiona Tran

**Vietnamese-Australian Autism Support Group of
Melbourne**

**The Vietnamese Parents with Disabled Children
Support Group in NSW (Australia)**

<http://chamevoiconkhuyettat.org.au/>

Family and friends of CLAN

who support us every step of the way!

www.clanchildhealth.org



clan

Caring & Living As Neighbours



Putting Children and Adolescents
on the Global Non-Communicable
Disease Agenda

www.ncdchild.org