



# Clan

Caring & Living As Neighbours



# Annual REPORT

July 2015 – July 2016



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Australia

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On 27 May 2011, CLAN was formally accepted as a signatory to the Australia Council for International Development (ACFID) Code of Conduct. CLAN is committed to improving international development outcomes and increasing stakeholder trust through enhanced transparency and accountability.



ACFID  
MEMBER



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# President's Message



Dr Kate Armstrong

For over a decade, CLAN has been responding to the priorities of communities of children, adolescents and their families living with Non-Communicable Diseases (NCDs) and other chronic health conditions in low- and middle-income countries (LMICs) around the world. CLAN's five pillars and strategic framework for action have consistently stood the test of time, helping us focus resources and energies on collaborative activities and initiatives that address community needs and concerns.

As a rights-based organisation, CLAN has long viewed our work in the context of society's collective responsibility to protect and promote the rights of EVERY child to health and life. More recently we have used CLAN's five pillars to inform a practical understanding of the United Nations Convention on the Rights of the Child (UNCRC) and promote community awareness of the many ways UNCRC affirms collaborative efforts for the benefit of children and adolescents living with chronic health conditions in LMICs.

*This process has been a powerful reminder that CLAN's work must continue as a matter of justice – not just charity.*

We hope you enjoy reading about some of CLAN's activities over the last year. We thank our many inspiring and committed partners around the world for working with us to promote community empowerment as a driver of sustainable change at local, national, regional and international levels. It is a pleasure working together so that all children and adolescents living with chronic health conditions might enjoy the highest quality of life possible. Let's continue our collaborative efforts to #LeaveNoChildBehind!

**President and Founder of CLAN – Dr Kate Armstrong**

# About CLAN

Dr Kate Armstrong founded CLAN in Australia after learning of the plight of children living in Vietnam with the same chronic health condition her own child was diagnosed with as a baby. Because Kate and her family lived in Australia, their baby had access to regular medication and quality healthcare, and therefore able to live a happy and healthy life. After reading heartbreaking stories from Vietnam, Kate wanted to understand more about the barriers to children living with chronic health conditions in less developed countries enjoying the same quality of life as her own child.

In 2004, Kate teamed up with like-minded doctors, hospitals and volunteers and CLAN's work began by helping children living with Congenital Adrenal Hyperplasia (CAH) in Vietnam in response to stories in Australian and American CAH support group newsletters that outlined the shocking global inequity that existed for children living with CAH.

*While a child in Australia with CAH could expect a high quality of life, children in Vietnam were dying and suffering unspeakable disability.*

Early success helping children with CAH in Vietnam led to requests for assistance from health professionals and families to help children with CAH in the Philippines, Indonesia and later Pakistan.

In 2016, CLAN was invited to help children with Diabetes in Vietnam, followed by Autism, Nephrotic Syndrome, Osteogenesis Imperfecta and Duchenne Muscular Dystrophy. CLAN's Strategic Framework for Action is founded on a rights based community development approach with a focus on five key pillars is instrumental to CLAN's success.

## Our Vision

That all children living with chronic health conditions in resource poor countries of the world will enjoy a quality of life on par with that of their neighbours' children in wealthier countries.

## Our 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.

## Office Bearers



**President  
and Founder**  
Dr Kate Armstrong



**Treasurer**  
Heidi Armstrong



**Vice President**  
Cath Cole



**Public Officer**  
Valerie Foley



# Governance Framework

## Accountabilities:

CLAN is proud to adhere to national and international ethical practice, informed by the following standards:

- IFRCRC – (International Federation of Red Cross/ Red Crescent Societies) Code of Conduct
- WANGO – (World Association of Non-Government Organisations) Code of Ethics and Conduct for NGO's
- ACFID – (Australian Council for International Development) Code of Conduct
- ACNC – (Australian Charities and Not for Profit Commission)

We align our work and professional practice in accordance with:

- United Nations Convention on the Rights of the Child
- United Nations Sustainable Development Goals
- The Sphere Project Humanitarian Charter
- ACFID NGO Effectiveness Framework (June 2004)

## Funding:

The CLAN donor community is at the heart of what we do. We acknowledge and express our gratitude and appreciation to all of our supporters who enable us to achieve numerous significant and global outcomes.

We rely on the generous support of our donor community to continue improving the quality of life of children and families with chronic health conditions in resource poor countries. Through regular and one-off donations, fundraising events, corporate sponsorships and government grants, donors have funded many projects to give a voice to children and families living with debilitating chronic health conditions.

We ensure that our relationship with our donor community is built on trust, transparency and is ethical in every sense of the word. We seek to establish and maintain high standards of ethics amongst our members, staff and volunteers by adhering to the following ethical principles.

- Honesty
- Empathy
- Respect
- Transparency
- Integrity

*It is with appreciation and gratitude that we thank our loyal community of supporters so we can continue to change the world together.*

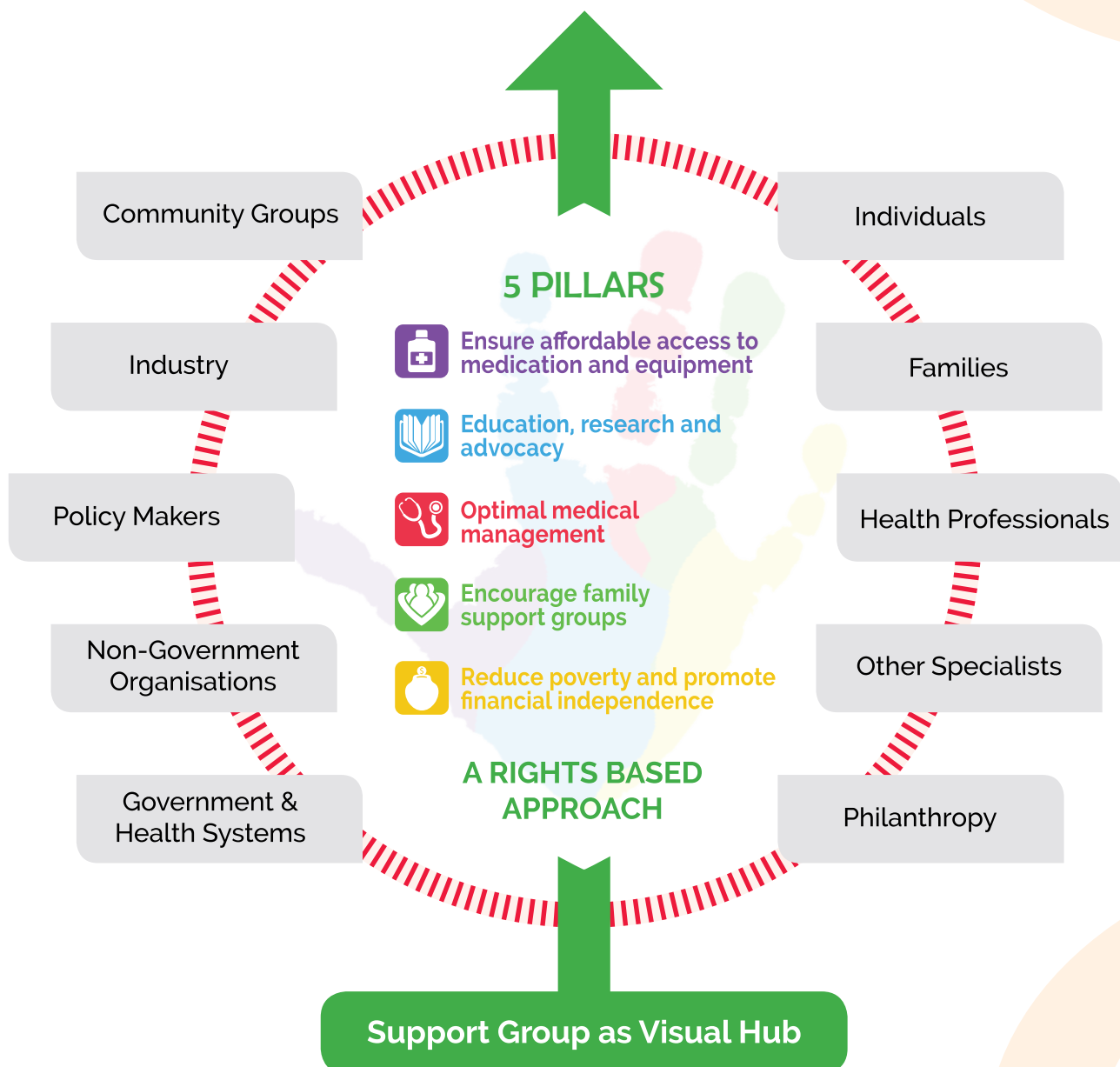
# Strategic Framework for Action

## We are all RESPONSIBLE!

We believe in working together to effect change on a global scale for children and adolescents living with chronic health conditions. It is vital that we all strive for this, because the children and families themselves are virtually powerless to effect change without the help of their neighbours, friends, health care professionals and concerned global citizens.

*Our rights-based, grassroots community development approach provides a strategic framework for action that focuses on multi-sectional collaboration on our 5 Pillars.*

## Highest Quality of Life



# CLAN's Global Footprint

## Support Group Meetings

### Australia:

- CLAN founded in 2004

### Kenya:

- Second Rheumatic Heart Disease Club Launched in Machakos as ongoing commitment to the UN Secretary General's Every Woman Every Child Campaign

### Pakistan:

- Pfizer Australia Grant key to achieving successful outcomes in Pakistan; App for CAH families and medical practitioners, employment of a CLAN Community Development Officer on the ground at the National Institute of Child Health; created a short film about CAH in Pakistan and the work of CLAN
- Pakistan has the world's highest number of Polio cases. New focus on improving the quality of lives of children living with Polio in Pakistan

## Snapshot of 2015-2016 Highlights

### Donated important medicines:

- Solucortef to Indonesia
- Developing surgical rods for children with Osteogenesis Imperfecta in Pakistan in collaboration with Children's Hospital Westmead

### Published in 2015-2016:

- Diabetes Rights Flyers in Spanish and French
- Childhood Cancer Rights Flyer in English
- A submission to the UN Secretary General's High Level Panel on Access to Medicines

### Developed:

- The position of Community Development Officer in Karachi, Pakistan through the support of a \$25,000 donation from Pfizer Australia. Through this grant, we have been able to:
  - Employ a full-time Community Development Officer at the National Institute of Child Health
  - Develop a register of CAH families
  - Develop an App specific for families and medical professionals

Guyana

Pakistan

We have 20

volunteers internationally

- We have translated and published resources in Spanish, French, English, Urdu and Indonesian.
- We have provided opportunities for 7 International interns through Global Experiences.
- We are represented in global working parties to create change in global healthcare for children and families with chronic health conditions.

Kenya

Mali

Indonesia

### Travelled to:

- Pakistan to meet with Doctors from the National Institute of Child Health in Karachi
- Vietnam to attend Nephrotic Syndrome Club Meetings

### Secured commitment from:

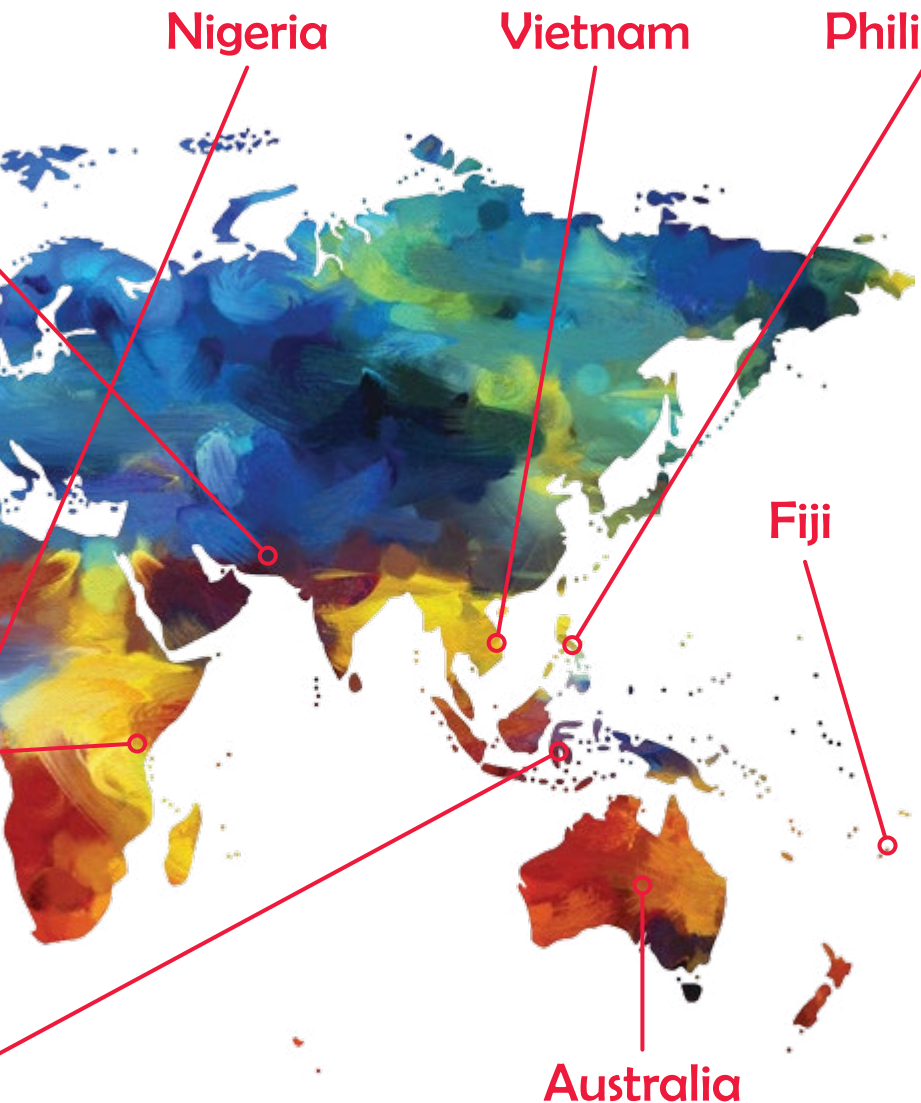
- The Pakistani Government and Health Minister during the Childhood NCD Conference in Karachi in December 2015 to supporting newborn screening for congenital hypothyroidism
- Honorary Consul for the Australian High Commission to attend support group meetings in Pakistan

### Presented at the following international conferences:

- Pakistan – Childhood NCD Conference in Karachi December 2015



# Who we work with



Since 2004 we have been working around the world to establish support groups for children and their families living with chronic diseases.

- Fiji since 2016
- Nigeria since 2014
- Kenya since 2011
- Pakistan since 2007
- Indonesia since 2006
- Philippines since 2005
- Vietnam and Australia since 2004

We work to create change and improve quality of life for children living with:

- Congenital Adrenal Hyperplasia
- Osteogenesis Imperfecta
- Diabetes
- Autism
- Duchenne Muscular Dystrophy
- Nephrotic Syndrome
- Polio
- Rheumatic Heart Disease
- Congenital Hypothyroidism

Who we work with:

- United Nations Department of Public Information for NGO's
- United Nations Every Woman Every Child Movement
- APPEP (Asia Pacific Paediatric Endocrinology Society)
- Global Paediatric Endocrinology and Diabetes
- NCD Child
- Life for a Child – International Diabetes Federation
- Pfizer Australia
- DFAT, The Australian Department of Foreign Affairs and Trade
- Children's Hospital Westmead
- National Institute of Child Health in Karachi Pakistan
- Sydney Children's Hospital Network
- Australia/New Zealand Paediatric Nephrology Association (ANZPNA)
- Wishbone Day
- TI International
- AYUDA
- Atfaal Welfare Society
- Sante' Diabete





# Pillar 1:

Affordable Access

to Medicine and Equipment

## Saving lives with Solucortef in Indonesia

In 2015, CLAN collaborated with APES (the Asia Pacific Paediatric Endocrinology Society) to develop a survey of paediatric endocrinologists living in the Asia Pacific to learn more about the challenges and burdens facing children living with endocrine conditions in the region.

From the survey, we learnt of the relatively high rates of preventable mortality associated with Congenital Adrenal Hyperplasia (CAH) in Indonesia. We investigated further and discovered that children and families in Central Java were unable to access Hydrocortisone for injection, and as a result, an estimated 12% of children with CAH were dying due to acute illness from untreated adrenal crises. By comparison, mortality associated with CAH in Australia and other high income countries is almost 0%.

We were proud to work in partnership with members of the Indonesian CAH Community KAHAKI, doctors in Central Java and the Indonesian Paediatric Endocrinology Society to urgently address this humanitarian emergency.

A one-off purchase of 50 vials of Solucortef (Hydrocortisone for injection manufactured by Pfizer Australia) from the Children's Hospital Westmead, Sydney Australia was immediately dispatched to Dr Agustini Utari in Central Java. A further 50 vials were dispatched later in the year.

Dr Utari then worked with her colleagues to develop a local distribution plan that incorporated extensive education for families and health professionals, and within a month all families of children living with CAH in the region had access to emergency treatment for CAH.

Since starting this program, no child given access to these vials has died. Encouragingly, the Indonesian Paediatric Endocrinology Society is also leading national efforts to register Hydrocortisone for injection in all hospitals and include the drug in national formulary and insurance lists so that it is locally and affordably available to all in the future.

Without this collaborative action, more children would have died unnecessarily. We would like to thank all involved in this project for the lives they have saved. Thank you so much for caring for our neighbours' children as if they were your own.



# Taking Ownership: A True Story, by Salman Munir Pakistan

I am writing from the perspective of a young person living with CAH in Pakistan. I mean we all cannot stay quiet and just hope for a miracle. We need to work to make a change so I decided to speak out regardless of how it will turn out for me. Even though my parents told me not to highlight myself time and time again, I believe the more we hide the greater our problems become. I will share a story about the family of a child with CAH who suffered great loss because they worried more about hiding their child's illness than learning about it.

Many families in my country try to hide their child's illness. My parents did this too. Like all parents, they love and care for me. They always tried to protect me. To the point that we made a nick name for my medication so that if my parents had to remind me of my medication they used the nick name and asked me if I have met him (the nick name) or not. I would understand their coded way of asking me if I'd taken my medication or not.

This story is about a family similar to my own, but different. Like my parents, they had a child born with CAH, but in their case, they wanted to hide their child's illness from everyone and were not even willing to discuss it with anyone – not even with me or my parents even after we shared with them explicitly that the child and I have the same condition. They were never ready to talk to us. This family's 7 month old child had been falling sick over and over again since birth. Since that family lived in a country where basic healthcare was not that great they had to make trips to Pakistan for treatment when the child fell severely ill. After multiple trips to Pakistan they finally learned that their child had CAH.

One day their child fell acutely ill and they had rush to get on a flight to Pakistan. The child was deteriorating very fast. I learned about the child whilst the family was travelling. As soon as I got hold of the child's parents I informed them to come to the city I was at so that I could be there and talk to their doctor. On their way, even though the child was vomiting severely, the parents were still administering the medication through the mouth. They knew about stress dosing but they were not informed about the need for emergency injections with hydrocortisone when the child is not able to take the medicine orally. The doctor was an endocrinologist trained in the United States but was relatively new to the illness in terms of

its management. Eventually the parents made it to Pakistan but when I contacted them they were not interested in talking to me. The reason was that they did not want people to know about their child's CAH and did not want to own that their child was suffering from an illness that could prove to be fatal if not managed well. They were new parents to this illness and had no idea about it. They told me they were in contact with their doctor who was in the other city, and yet they were not willing to go to that city because their extended and immediate family lived in the very same city as the doctor, and they worried the family may discover their child has CAH if they went to the city. In fact, they told me explicitly not to tell anyone about the situation and were more concerned about hiding their child's CAH than managing it.

Now that the parents were in Pakistan they were not able to assess that their child needed hospitalization and that their child was so severely dehydrated that he needed multiple fluid transfusions. Instead of admitting the child to the hospital they kept the child at home and when I asked them they told me they are fine and are in contact with their doctor. Finally, a few days after they got to Pakistan the child's condition worsened to the point that the child developed seizures and was taken to the hospital. And a little while later the child passed away.

The moment I learnt the child had passed away it not only made me sad that we had to lose a child to an illness that was nothing but a simple hormonal disorder like Diabetes which just needed prompt management, but it also made me angry. Angry at the fact that we as a society are so narrow minded that we are afraid to even discuss our illnesses even in times when someone is crashing. We are more concerned that if someone knows about it the future will be destroyed not putting faith in destiny.

In this short sad story, I also want to tell you something that might give you a ray of hope if not much. I too was born with classical salt wasting type CAH in the time when there was no CAH community in Pakistan. In fact, there was no paediatric endocrinologist in the country. My

## Congenital

### Adrenal Hyperplasia (CAH)

Is a rare genetic disorder, present at birth, involving the hormones of the adrenal glands. The word 'hyperplasia' means 'overgrown'. A child with CAH is born with overgrown adrenal glands. In developed countries, the disorder is well understood and treatment readily available. In resource poor countries however, children born with CAH are not so lucky. This is a true, very personal story from one of CLAN's collaborators, about living with CAH in Pakistan.

parents went out of their way to learn about it. I grew

up in a very secure family. I always questioned myself; why do I have CAH and am not like the other kids in my school? Why did I look different? All these questions kept popping up and I had no answer to them. The only I answer I got from my parents was there is something big waiting for you which we do not know ourselves. It was only when I got into med school that things started to make sense. From there I started to learn about my condition and that day I decided to learn about it so I could help the people suffering from it. Had it not been for my illness I would not have known all the doctors that I know. Nor would I be helping other people who are suffering from CAH. Sometimes we are too occupied thinking negatively that we are not able to see the positive side to things. Sometimes all you need is time.

Every cloud has a silver lining, but it's only a few who are able to see it. Only those who look hard and don't settle for less are able to see it eventually. The most important first step to finding the silver lining is that you must start owning something before you can work on it.

Amongst the many research articles I have read on CAH, one was an article that showed people with CAH have higher IQ. So I ask all those who are hiding why do you feel the need to hide when most of us are smarter than the average group of people? Don't ruin your mind and IQ by having a negative outlook. You are beautiful and smart - live it and express who you are. OWN YOUR SELF COMPLETELY.

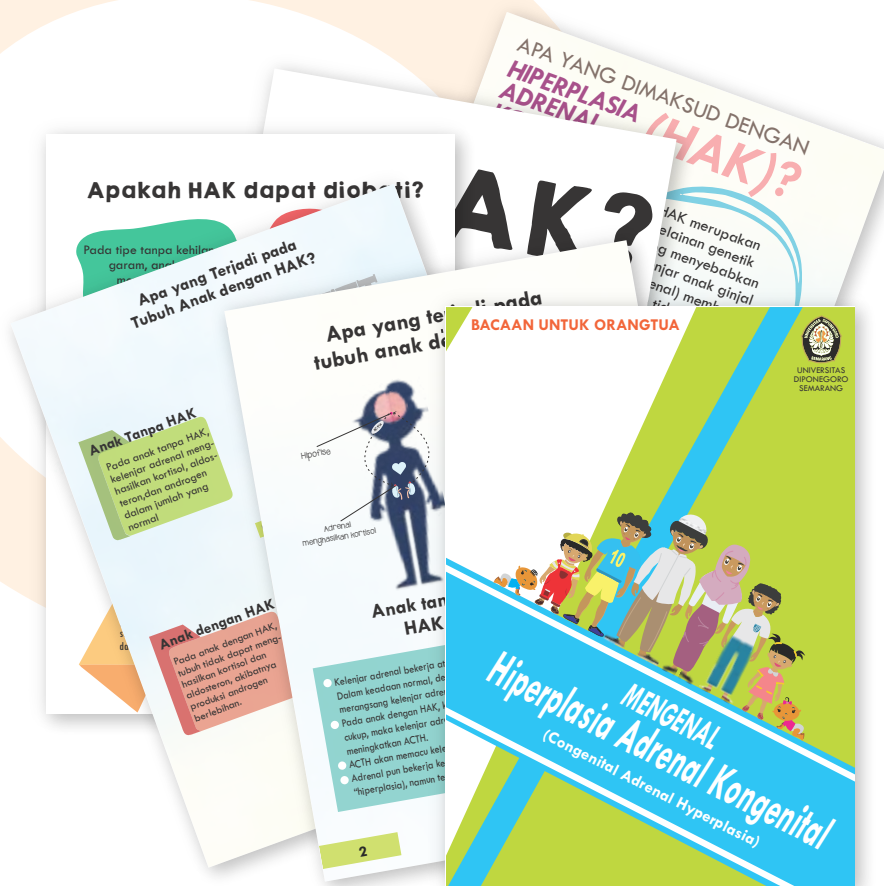
*There are an estimated 400 people living with CAH in Pakistan.*



# Pillar 2:

Education

Research and Advocacy



## Educating Health Care Practitioners and Families in Indonesia

Dr. Agustini Utari is a paediatric endocrinologist practising in Indonesia who works closely with CLAN to improve the quality of life of children living with CAH. Dr Utari revealed that the *“endocrinology of CAH is not included in competency requirements for general practitioners [in Indonesia]”*.

A big priority for Dr. Utari is the education of primary healthcare practitioners in her community, including midwives and prenatal healthcare providers. Dr. Utari has teamed up with psychologists in her area to research the level of education about Congenital Adrenal Hyperplasia in Indonesia. She and her partners found that

*“approximately 70% of babies born in Indonesia were delivered in the homes of midwives or in clinics managed by midwives”*.

With this information in mind, they set out to survey these midwives about the protocol they use to determine the sex of a newborn child. The research showed that *“most patients with ambiguous genitalia are late identified... and about 50% of midwives didn’t know about ambiguous genitalia, which can cause an emergency situation in some cases”*.

The next step is to *“educate general practitioners in primary health care...especially in remote areas [because] there is no specialized practitioner at all; more education to primary health clinics about CAH is important”* and can potentially save the life of a child in the midst of an adrenal crisis.

2015, Dr Utari and her colleagues developed an educational resource booklet for CAH patients and their families in Bahasa Indonesia. Dr Utari and her partners have enjoyed great success using the booklet to educate families.

The booklet is being used in a *“simple education approach”* for the small groups that have been meeting in central Java. *“This group setting is different from the Jakarta setting; most patients are from a low education and low socioeconomic background. We tried to make a simple booklet with more pictures to make it easier to understand,”* said Dr. Utari.

The support group for CAH families in Central Java has started to meet in smaller, more personal groups of four to five families. In the larger groups, families were only able to receive brief education about their child’s condition and circumstances. Within this smaller group that has been meeting, families have had a better opportunity to share their experiences with other families and go over the new booklet together. Dr Utari shared that previously, many families felt as though they were experiencing the hardships and milestones of raising a child with CAH alone, but these small groups have given them the reassurance that they have the support of their local CAH community.

As many families are from lower socioeconomic backgrounds, many parents are illiterate so this new booklet including pictures and easy to understand explanations for parents and children makes it easier to comprehend the information being provided.

This booklet is now being shared with parents to better understand CAH. Dr Utari and her team are developing a one-year plan for small group meetings and other activities so families can provide support for each other and learn more about the different milestones of living and thriving with CAH.

# What are the Rights of the Child Living with Diabetes?

All children around the world should have, or be able to have the same rights. These rights are provided for by the United Nations Convention on the Rights of the Child (UNCROC) 1989.

The United Nations recognises that as a child you should be fully prepared to live an individual life in society and be brought up in the spirit of happiness, love, understanding, peace, dignity, tolerance, freedom, equality and solidarity.

As a child with Type 1 diabetes you have the right "to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health". It is the responsibility of the international community to ensure that countries "strive to ensure that no child is deprived of his or her right of access to such health care services".

Children, young people and their families living with diabetes and other chronic health conditions in low- and middle-income countries ask for the rights of children. Fortunately, UNCROC recognises...



**What do families and young people living with diabetes ask for?**

"We need affordable access to medicine and equipment"



"We need more education, research and advocacy"



**Your rights and responsibilities under the United Nations Convention on the Rights of the Child (UNCROC)**

- The inherent right to life (Article 6).
- Governments recognise that a child living with a mental or physical disability should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate your active participation in the community ... and ensure access to health care services and rehabilitation services (Article 25).
- The right to the enjoyment of the highest attainable standard of health and facilities including the provision of necessary medical assistance and health care (Article 24).
- The right to express your views and be heard in judicial and administrative proceedings that affect your rights (Article 12).
- The right to information and material aimed at promoting your physical and mental health and to ensure appropriate guidelines to protect you from information and material that is injurious to your wellbeing (Article 17).
- The right to be informed, have access to education and be supported in the use of basic knowledge of child health and nutrition (Article 26).
- The right to education directed at the development of your personality, talents and mental and physical abilities to the fullest potential and the development of respect for human rights and fundamental freedoms (Article 28).



**What do families and young people living with diabetes ask for?**

"Family support group meetings help us a lot"



"We are poor - my family needs financial independence"



**Your rights and responsibilities under the United Nations Convention on the Rights of the Child (UNCROC)**

- You and your family have the responsibility to help you learn to exercise your rights (Article 16).
- The right to freedom of association (Article 15).
- Governments recognise that a child living with a mental or physical disability should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate your active participation in the community ... and the right of the child living with a disability to special care, subject to available resources, for you and those responsible for your care (Article 23).
- Governments shall undertake all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the present Convention ... to the maximum extent of their available resources and where needed, within the framework of international co-operation (Article 4).
- The right to benefit from social security, including social insurance (Article 24).
- The right to a standard of living adequate for your physical, mental, spiritual, moral and social development (Article 27).
- The right to education (Article 28).



## Why Do Children Living with Type 1 Diabetes Need Insulin and Supplies?

Some people have Type 1 diabetes. This means their pancreas doesn't produce insulin.

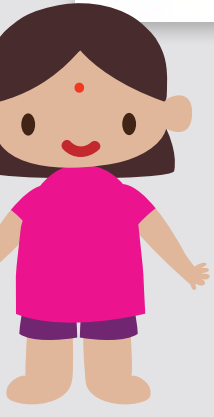
People with Type 1 diabetes need to take insulin several times a day via injection.

Insulin is the key that allows the body to use sugar (carbohydrate) as energy.

Constant monitoring of blood sugar levels and carbohydrate intake is part of life with Type 1 diabetes.

Managing diabetes is a complicated task even with the best tools and technology.

Some people still cannot access their essential insulin or diabetes supplies.



## Promoting and Protecting the Rights of Children Living with Type 1 Diabetes

Type 1 Diabetes is a life-long autoimmune disease that usually occurs in childhood but can be diagnosed at any age. In Australia alone, Type 1 Diabetes affects over 120,000 people but is easily managed.

To celebrate World Diabetes Day in 2015, CLAN worked with a range of partners (TI International, IDF Life For A Child, NCD Child, Atfaal Welfare Society, AYUDA and ONG Santé Diabète) to develop a child friendly flyer that can be shared with communities of children and families living with diabetes to help them understand more about their rights and responsibilities as provided for by the United Nations Convention on the Rights of the Child.

We have been proud to work in partnership with the International Diabetes Federation's Life For A Child (IDF LFAC) program and ONG Santé Diabète to advocate for children and adolescents living with Type 1 Diabetes in Mali.

During the inauguration of a new clinic for Type 1 diabetes at the national hospital in Mali, a young girl who is living with diabetes in Mali proudly presented a copy of the flyer to the World Health Organisation Country Director; a representative of the National Assembly of the Republic of Mali; and Cabinet Director and Hon Minister of Health of the Republic of Mali.

The Diabetes Rights Flyer is a credit to the many partners working together in Mali and around the world to promote and protect the rights of children living with T1 Diabetes. Special thanks and acknowledgements must go to Stéphane Bescanon, Director General of ONG Santé Diabète for his incredible leadership and vision, translating the flyer into French; to the team at TI International for translating it into Spanish; and also to Amy Eussen, CLAN's United Nations Consultant, for her wonderful generosity of spirit, sharing invaluable legal expertise to benefit the communities CLAN works with.

# Guyana Fellowship Report

## Strengthening Community Support Groups to Address Non-Communicable Diseases in Guyana

In September 2015, CLAN was awarded funding through DFAT to host a fellowship program to strengthen national efforts to support children living with NCDs in Guyana utilising CLAN's rights-based, community development model.

The fellowship was awarded to CLAN based on the organisations' experience supporting interventions to support civil society organisations address non-communicable diseases (NCDs) in children in South Asia for several years. The learnt knowledge and experience allowed CLAN to initiate, plan and support the Guyana fellowship.

Two fellows from the University of Guyana were funded by the fellowship, Rev Noel Holder, Head of Department, Public Health University of Guyana, and Dr Barbara Reynolds, Deputy Vice Chancellor University of Guyana. Mrs Bridget Hinds, a Guyanese-American and associate in the NCD space joined the fellows and was self-funded.

### Planned Outcomes:

1. Fellows have a comprehensive grasp of the situation of children affected by NCDs in Guyana, including and particularly the factors affecting the growing incidence of NCDs among children, the levels of public knowledge and awareness, and efforts within the non-government sector to promote the protection of and support for these children.
2. Enhance knowledge within the non-government sector about the growing incidence of NCDs, and initiatives that can be developed to prevent and mitigate their impact among children.
3. A shared consensus within among non-government actors about the areas requiring research and/or advocacy to promote and protect the well-being of children affected by NCDs.
4. Outlines of two courses on addressing NCDs (aligned to the NCD chapter in Facts for Life), one for health professionals and practitioners, the other for non-health professionals and practitioners that routinely interact with children and adolescents, that can be offered as regular (for credit as part of a degree programme) and special courses (not-for-credit for special interest groups) at the University of Guyana.
5. Synergies across Fellowship, NCD Child, UG and national partners' activities in Guyana.
6. Ideas on further collaboration within the region and with CLAN.





Pictured, left to right: Rev Noel Holder, High Commissioner John Pilbeam, Dr Barbara Reynolds, Ms Jackie Lauff (Sport Matters), Ms Brigette Hinds and Dr Kate Armstrong.

## Achievements

The achievements of the fellowship were both tangible and intangible, the latter being the insights and perspectives and exchanges that have spurred and stretched our thinking in various directions. The specific achievements are the basis for future collaboration in many areas.

### Outcome 1

Prior to the visit to Australia, the Fellows had prepared a brief analysis of the situation of NCDs and Children/Adolescents in Guyana. In preparing this sitan, a formal meeting was held with the Minister in the Ministry of Public Health, the Coordinator of the NCD programme and other officials to gain a better understanding of the Government's strategy and to brief the Ministry officials on the fellowship. There were also several exchanges with the NGOs involved in NCDs, CARICOM and the Davis Memorial Hospital (the sister hospital to the Sydney Adventist Hospital).

### Outcome 2

The Fellows put together a number of background documents for the proposed National Consultation of Civil Society on NCDs. The Fellows also reached out to the health Caribbean Coalition and collaborating on NCD Child's Advocacy Workshop (Lima, Peru) in terms of developing an approach for the consultation.

### Outcome 3

This is the primary focus of the National Consultation, now slated for February 2016.

### Outcome 4

One course outline for health professionals has been drafted; the other is under development.

### Outcome 5

The greatest gains are in this area where the Fellows were able to establish working relationships and create the potential for future collaboration with a number of Australian entities.

### Outcome 6

CLAN's Strategic Framework for Action is being explored for use with NGO's in Guyana, and the Fellows hope to invite CLAN to present at the National Consultation. The Fellows have reached out to the Healthy Caribbean Coalition and have already seen results from this networking in the form of the inclusion of the University of Guyana in a proposal to the (US) National Institutes of Health for a Centre of Excellence Research on NCDs.

By Doctor Barbara Reynolds

## Dr Reynolds, Deputy Vice Chancellor, says...

"Meeting Australians passionate about the prevention, treatment and care of children and adolescents affected by NCDs, and about the linkages between research, policy and practice in the same space was truly inspirational. We came away impressed by the energy that our discussions generated, the endless possibilities to make a difference, and the reaffirmation about what's best about our collective human project - that despite social differences, fundamentally we all want to grow up happily and healthily, find a great vocation, raise a fabulous family and help those most in need! As we return to Guyana, we remain committed to our aims of linking research, advocacy and technical assistance to enhance the contribution of non-government actors in Guyana. Thank you DFAT, CLAN and friends!"

### Meetings and visits were undertaken with the following:

- Westmead Children's Hospital
- Seventh Day Adventist Regional Headquarters
- Ronald McDonald House
- Westmead Children's Hospital
- Epilepsy Action Australia
- Victoria State Department of Education
- University of Sydney
- Exchanges with medical students
- Aboriginal Health & Medical Research Council, Wentworth Ave Surry Hills
- University of Canberra
- Department of Foreign Affairs and Trade, (DFAT) Canberra
- Office of the Advocate for Children and young People
- University of New South Wales
- Avondale school, Avondale College and Macquarie School





# Pillar 3:

## Optimisation

## of Medical Management



### Key Recommendations from the Inaugural Pakistani NCD Child Alliance Advocacy Workshop

In December 2015, Dr Kate Armstrong CLAN President and Cath Cole Vice President, travelled to Pakistan to participate in the 7th Annual Symposium of the National Institute of Child Health. Themed *Non-Communicable Diseases (NCDs): Challenges for resource poor countries*, the Symposium offered a unique opportunity for a range of eminent paediatricians, government officials, multilateral and international experts in the field of child health and NCDs to come together in a pre-symposium workshop and discuss opportunities to strengthen a life-course approach to NCDs in Pakistan.

The *NCD Child Alliance Advocacy Workshop* participants explored the role of paediatricians, government and other stakeholders in addressing key challenges relating to NCDs, children and adolescents in resource poor countries. There was a specific focus on childhood obesity and under-nutrition; tobacco control; and other opportunities to reduce the preventable morbidity and mortality associated with childhood NCDs.

Six key recommendations for action emerged from discussions with regards opportunities for paediatricians, government and other stakeholders to strengthen and support a life-course approach to NCDs in Pakistan:



#### 1 Leadership

- Paediatricians have a responsibility to understand NCDs and their risk factors as well as diagnose NCDs effectively
- Paediatricians must adopt strong leadership roles in promoting a life-course approach to NCDs in Pakistan
- There is a need for ongoing discussion and action in this space, with suggestion that a dedicated working group (with support of the Pakistani Paediatric Association) assume a key leadership role in this regard

#### 2 Awareness and advocacy

- There are strategic opportunities through continuing medical education (CME), and revision of medical and school curriculums to promote awareness amongst health professionals around NCDs
- Paediatricians play five key roles in society: counsellor; teacher; advocate; leader and physician.







As such they enjoy a range of opportunities to raise awareness around NCDs and advocate for change

- Paediatricians have a responsibility to raise awareness about and advocate for child rights
- Paediatricians must advocate for changes to the health care system and government policies as needed to protect children and adolescents who are living with and at risk of NCDs
- At the grass roots level paediatricians are responsible for ensuring families are aware of resources and support groups available to them

### 3 Prevention

- Acknowledging the developmental origins of health and disease, action across the life-course must focus particularly on the health of the girl child, nutrition of adolescent girls, nutrition during pregnancy, promotion of breastfeeding, empowerment of women and support for strong vaccination programs
- Children and adolescents must be engaged in physical activity. This should be encouraged by parents and health professionals, but also through the school curriculum
- Smoke free schools and nearby areas should be mandatory, with no display of cigarette packaging or tobacco products at counters
- Newborn screening is essential to the early and cost-effective diagnosis and appropriate management of several childhood NCDs
- Electronic tools and technology are increasingly available and opportunities to harness the power of innovative technologies should be explored
- Safe external environments that allow women and children to exercise and play safely are a fundamental right and require greater investment

### 4 Diagnostics and treatment

- Government has responsibility to ensure affordable access to essential medicines and equipment needed to optimally manage childhood NCDs
- Adolescent health and well-being presents unique challenges and must receive specific consideration
- Government has a responsibility to support health professional development and ensure quality health facilities are available to communities
- Invest in social protection mechanisms to protect families from financial ruin where children are diagnosed with NCDs

### 5 Collaboration

- NCDs affect everyone in society. The nation, as a whole must be involved in driving solutions for change, including: the media, community groups, civic society, religious leaders, police, shopkeepers, youth, legislators, educational institutions and all levels and sectors of government
- Paediatricians have a respected role in the community and enjoy a unique position that allows them to engage with a broad range of stakeholders, from children and families at the grassroots level to policy makers, multilateral and international experts
- Government needs to be receptive to information provided by subject matter experts and consider this when implementing or reviewing policy. Any new legislation should be developed through wide consultation across the stakeholder group and implementation of resultant policies must then be supported by all stakeholders to ensure effective roll-out
- Intersectional and multi-level communication and collaboration will ensure the right mix of professionals and stakeholders

### 6 Monitoring, reporting, research and accountability

- There is an urgent need to develop a comprehensive national research agenda that will provide national data to inform local programs and policy directions in future. Identification of the childhood NCDs associated with the greatest burden in Pakistan must be an early focus
- Government should take a position of 'ownership' of policy and exercise vigilance in monitoring to ensure accountability. NCD budgets must include funding to support formal evaluation and monitoring processes. All reviews should be target oriented to ensure specific areas of risk are reviewed and tested
- Doctors and government officials must always demand the highest ethical standards of themselves
- Tobacco legislation should be enforced and strengthened so as to optimally promote and protect the rights of children and adolescents to smoke-free environments
- Strong legislation must stop marketing of unhealthy food and drinks to children



# A Focus on Medical and Surgical Management of OI in Pakistan

the  
children's  
hospital at Westmead

The Sydney children's  
Hospitals Network

In 2015, CLAN partnered with the Children's Hospital in Westmead as well as the team at NICH in Pakistan to improve access to bisphosphonates and explore development of surgical rods to strengthen bones in affected children. The rods are currently in prototype phase and work will continue on this project in 2016-2017, along with onsite training of Pakistani doctors at the Children's Hospital in Westmead in early 2017.

Osteogenesis Imperfecta (OI) is the most common congenital bone fragility disorder with an incidence of approximately 1:20,000. It affects all races with an equal sex distribution. Children with OI are often born with long-bone and vertebral compression fractures. Untreated, these children will continue to have numerous non-traumatic fractures per year that results in bone deformity, spinal curvature, reduced motor function, chronic pain and premature death.

Medical treatment of OI centres on the administration of intravenous bisphosphonate. This medication has been used to improve bone density and strength in OI patients for the past 20 years. It has been shown to reduce pain, improve quality of life and reduce life-threatening heart and lung complications.

Surgical management centres on setting of fractures and straightening of bent long-bones and spine. For optimal care, medical and orthopaedic services cannot work in isolation. Optimal treatment of OI relies on a coordinated interdisciplinary approach with input from endocrinologists, orthopaedic surgeons, geneticists, rehabilitation specialists, radiologists and allied health staff (physiotherapy, occupational therapy and specialist nurses). A coordinated approach leads to much greater health benefit than either surgery or bisphosphonate treatment alone.

Such a model of care is present in centres throughout Australasia, North America and some European countries. Over the past 5 years we have advocated the introduction of multidisciplinary OI teams in Asia, specifically Vietnam, Philippines and Pakistan. On a wider level, this model of care is taught at the annual Asia Pacific Paediatric Endocrine Society (APPES) Fellow School. This school is held on a rotational basis throughout Asia and brings together young paediatricians training to be endocrinologists. It offers the perfect opportunity to further disseminate treatment models. These workshops bring together the multidisciplinary teams from the host nation for intensive training and service development.

CLAN thanks authors Prof David Little and Prof Craig Munns.



# Nephrotic Syndrome Vietnam Club Report



When a child is living with a complex chronic health condition in a low or middle income country, it's very easy for the child and family to be "lost" within a healthcare system that isn't designed to effectively manage chronic health conditions. However, when a group of children with the same chronic health condition come together as a "community", suddenly, the impossible seems possible.

## What is Nephrotic Syndrome?

Nephrotic Syndrome (NS) is a chronic health condition of childhood in which the kidneys are damaged, causing them to leak large amounts of protein from the blood into the urine. The consequent drop in protein levels in the blood causes generalised swelling of the body often starting in the face, but then affecting the torso, limbs, and other parts of the child's body.

CLAN began working in the field of NS in Vietnam in 2010. In 2016 Dr Fiona Mackie from Sydney Children's Hospital, Randwick and Dr Amelia Le Page from Monash Children's Hospital in Melbourne travelled with CLAN to Vietnam for the first time.

During their visit, the following outcomes were achieved.

## Pillar 1. Affordable access to essential medicine and equipment

- 10 Biopsy needles were donated to medical practitioners in Hue, to respond to the lack of local capacity to undertake renal biopsies and have them reviewed locally without the need to transport samples to Ho Chi Minh City for analysis and reporting.
- Sodium Bicarb and Levamisole were identified as two major priorities for future access.

## Pillar 2. Education, research and advocacy

- CLAN's team was pleased to support Continuing Medical Education training for more than 200 health professionals on NS and other renal conditions of childhood at the largest children's hospitals in Vietnam. Topics discussed included NS, Lupus and chronic kidney disease.
- Future research into NS in Vietnam will be facilitated by the development of a database of patients which will replicate the database used in Australia.

## Pillar 3. Optimisation of medical management

- The CLAN team was pleased to visit the nephrology wards at the hospitals they visited and spoke to colleagues about the key challenges they face caring for children living with chronic renal conditions in Vietnam.

## Pillar 4. Encouragement of family groups

- A NS Club Meeting was held at Hue Central Hospital for approximately 100 members of the NS Community in Central Vietnam. Printed copies of the NS Vietnam Club Newsletter were distributed to all the families.
- A NS Club Meeting was held for the NS Community in North Vietnam. The meeting was attended by 150 families and began with a fantastic display of song and dance by the children. Families were presented with printed copies of a NS resource booklet that had been translated into Vietnamese.

## Pillar 5. Reducing financial burden and helping families achieve financial independence

- The vast majority of children with NS will outgrow the condition and lead a healthy and long life. It is important that children with NS are encouraged and supported to attend school and complete their education. Clear messaging about the importance of school was a feature at both NS Club meetings and awards were given to children for good school performance.

Special thanks Dr Fiona Mackie, Dr Amelia Le Page and Dr Elisabeth Hodson for dedicating their time and experience to help us achieve our mission.





# Pillar 4:

## Encouragement

### of community support groups

#### Pfizer Australia Supports Community Development in Pakistan

Through the generosity of Pfizer Australia, CLAN has been able to employ a full-time Community Development Officer at the National Institute of Child Health in Karachi, Pakistan. In late 2015 we welcomed Dr Rabia Baloch BDS, MPH to our team in Pakistan.

Before joining CLAN, Dr Rabia had been working on a variety of different projects launched by UNICEF to promote basic health in Karachi. Dr Rabia has a great understanding of the health care system of Pakistan and is passionate about bridging the gap between people and access to quality healthcare.

According to Dr Rabia, *"Pakistan is among those countries which are facing a "triple burden of disease", where NCDs share the major portion. Dr. Rabia is working with a team of experts at NICH to develop and empower communities of patients and families dealing with endocrine disorders.*

Endocrine disorders among children hold a critical status in NCDs and social and behavioural illnesses as well. She is currently engaged in a joint venture of CLAN and NICH to develop a community for Congenital Adrenal hyperplasia (CAH) including other disorders of sexual development, Diabetes Mellitus Type 1, Osteogenesis Imperfecta, Congenital Hypothyroidism and Childhood Obesity.

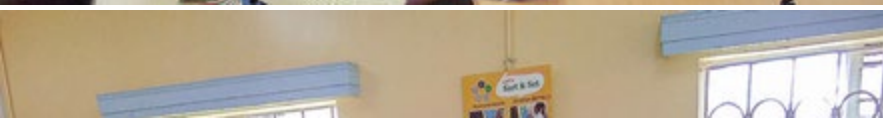
Considering the gravity of CAH and other NCD's in Pakistan, the team is dedicated to create awareness, disseminating knowledge and educating people regarding timely treatment and management. They are also scheduling club meetings for families addressing CLAN's 5 Pillars. Ensuring the availability of medications all over the country is a priority for the team and who have already submitted a proposal to the Pakistan Government.

The main objective is to build the capacity of the CAH community and to provide maximum support. In doing so, an electronic register for CAH has been developed bringing in many benefits for monitoring and evaluation of the treatment and to collate important research data. The registration of patients will begin from NICH followed by country wide registration of CAH patients. Similarly, development of electronic registers for other endocrine disorders is also in process.

To strengthen communication and networking between patients, families and doctors, a mobile App has been developed which will be available on Google Play and the App store to be launched in 2017. The App is based on CLAN's 5 Pillars and provides detailed information on CAH, growth hormone disorders, OI, Thyroid disorders, DB type 1 so that patients can easily resolve their issues and concerns.

Considerable effort is also going towards advocating for Polio as a disability and making it a priority. Dr Rabia is collaborating with Polio communities around the world to develop action plans and policies for the local Polio community.





## Expanding RHD Clubs in Kenya

Rheumatic Heart Disease (RHD) is the most common acquired heart disease in children in developing countries. It is estimated that approximately 15 million people are affected globally. RHD is closely associated with poverty and poor quality medical services. RHD is still a major problem in Kenya and children and their families have previously suffered in silence from this preventable condition. In 2014, CLAN launched the first RHD Club in Nairobi, and in December 2015, a second RHD Club was launched in Machakos. This collaborative action is part of CLAN's ongoing commitment to the UN Secretary General's Every Woman Every Child Movement.

## Support for Individuals Living with an Autism Spectrum Disorder

In 2015 we welcomed Tahni Aitkin to our Australian team. Tahni has been working in the field of Autism for the past 20 years and has worked in both Australia and the United Kingdom in early education for children on the Autism Spectrum.

Tahni joined CLAN in the role of Autism Community Consultant and worked to connect with resource poor communities who are supporting people on the Autism spectrum. In 2015/16, Autism Community Links were established in Uganda, Indonesia, Vietnam and the Bahamas, with a focus on connecting with Aboriginal communities in Australia also.





# Pillar 4:

## Encouragement

### of community support groups

#### The many faces of CLAN

As an Australian based not for profit organisation with global reach, we rely on the assistance of a dedicated group of volunteers from around the world who bring their diverse skills and energy to our services and administrative functions to help us achieve our outcomes. Our volunteers generously contribute their time, skills and passion, and we are extremely grateful to them all.



Professor Jamal Raza

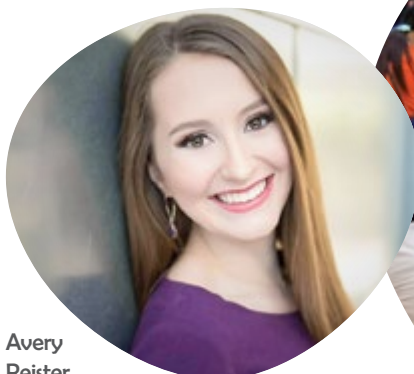
#### Avery Reister

- In 2015, we teamed up with Global Experiences for the seventh time. Global Experiences specialise in international internships and study abroad programs. Through this program, we welcomed Avery Reister from Cornell University in Ithaca New York. Avery was studying Urban and Regional Studies with minors in Business and Developmental Sociology and joined CLAN for a six-month internship to learn more about non-profits and the work we do connecting communities around the world.



#### Professor Jamal Raza

- Professor Jamal Raza is a graduate of Dow Medical College; a Paediatric Endocrinologist/ Professor of Medicine by training (London); Director of the National Institute of Child Health (NICH); Secretary General of the Pakistan Paediatric Association; President of SPED (the Society of Paediatric Endocrinology and Diabetes); incoming Chair of the Technical Assistance Group on NCDs (Non-Communicable Diseases) for APPA (the Asia Pacific Paediatric Association for Non-Communicable Diseases); and member of APPES (the Asia Pacific Paediatric Endocrinology Society). He has been instrumental in working with CLAN in Pakistan to improve the lives of children living with chronic health conditions.



Avery Reister





Irene  
Mitchelhill

## Honorary Associate Membership

CLAN is proud and honoured to present the Honorary Associate Membership for 2015-2016 to Irene Mitchelhill. Irene is a Congenital Adrenal Hyperplasia (CAH) Nurse Specialist in Australia. She has contributed to the CAH community in Australia enormously, and has committed to and attended CAH meetings in Vietnam and Indonesia. In 2015, Irene developed an online educational CAH resource for children, families and medical professionals which was subsequently translated into Indonesian, Vietnamese and most recently into Urdu for the Pakistani community. We thank Irene for her support of CLAN over many years.

### Celebrating Irene Mitchelhill: Honorary Associate Member

Irene has been a long-time supporter and valued volunteer of CLAN. Irene has worked in the area of paediatric endocrinology since 1980, developing expertise in the assessment of growth and development of children and adolescents with hormonal irregularities.

In September 2015, we were thrilled to learn that Irene had been awarded the Judith Meppem Lifetime Achievement Award at the NSW Excellence in Nursing and Midwifery Awards held at Parliament House, Sydney Australia.

The award publicly acknowledges the significant contribution that Irene has made to improving the health outcomes of patients and families in Australia and overseas through her professional commitment to the Nursing Profession over the past 43 years of her career.

In 2016, Irene was invited to contribute to the International Textbook of Advanced Practice Nursing in Endocrinology and was an invited speaker at the Asia Pacific Paediatric Endocrine Society (APPES) Continuing Medical Education Conference for trainees in Hanoi and Hue, Vietnam.

The quality of Irene's practice as a Clinical Nurse Consultant in Australia is outstanding and feedback from medical, allied health, patients and families reflect consistent excellent performance in all the domains of practice.

***Congratulations Irene – and sincere thanks from everyone at CLAN for your incredible contribution to CAH families in the Asia Pacific region!***

#### Key highlights of Irene's career include:

- Consultancy and development of the Emergency Hydrocortisone App, launched by Pfizer in March, 2014.
- Consultant to the Congenital Adrenal Hyperplasia Support Group Australia and support of Annual Seminar planning.
- Development of Growth Hormone DVD for families with growth problems: "Reaching their potential".
- Contribution to research with four first author papers; contributing author in two book chapters and involvement in two book reviews; invited speaker at the Endocrine Nurses Society Annual Conferences 2014 in Chicago and 2015 in Savannah, Georgia.
- Completed her Master of Nursing and presented internationally in Europe, South America and the USA.

#### Irene's contribution to CLAN:

- Support of CAH Club Meetings conducted by CLAN in Vietnam and Indonesia
- Launch of the CAH PepTalk website, a parent education website for Congenital Adrenal Hyperplasia that is available in English, Vietnamese and Indonesian (with an Urdu version in development).
- Worked with CLAN to develop a patient education DVD based on the CAH PepTalk program and shared with patients and families in Hanoi, Ho Chi Minh City, Vietnam 2012 and Jakarta, Indonesia 2012 (before internet access was widely available to families in these countries).



# Pillar 5:

Reducing poverty

and promoting financial independence

## CLAN's Ongoing Commitment to Every Woman Every Child

Launched by the UN Secretary-General Ban Ki-moon during the UN Millennium Development Goals Summit in September 2010, Every Woman Every Child is a global movement that mobilizes and intensifies international and national action by governments, multilaterals, the private sector and civil society to address the major health challenges facing women, children and adolescents around the world.

Over 300 organisations made commitments to advance the Global Strategy for Women's and Children's Health and we are proud to continue our commitment to this important campaign for change.

The theme for this year's International Day of the Girl was based on the seventeen Sustainable Development Goals developed as part of the strategy. The wellbeing, human rights and empowerment of the world's 1.1 billion girls are central to achieving the 2030 Sustainable Development Agenda. In that agenda, the UN promised girls quality education and health services.

The UN Secretary-General announced a commitment to ending discrimination and violence against girls, and harmful practices like child marriage. We all pledged to #leavenochildbehind.



Ban Ki-moon

UN Secretary General says...

"Too often, in villages, shanty towns and refugee camps around the world, girls are the ones left behind: without nutritious food, healthcare or quality education, and at risk of sexual violence. Investing in girls is both the right thing to do, and the smart thing to do. It has a powerful ripple effect across all areas of development, and reaches forward to future generations. But what cannot be measured cannot be managed. If we do not gather the data we need, we will never know if we are delivering on our promises. We need to make sure that our initiatives are reaching all girls: girls in extreme poverty; girls in isolated rural areas; girls living with disabilities; girls in indigenous communities; girls who are refugees or displaced within their own countries. Timely, high-quality data is vital so that we know where we are meeting our promises, and where we are falling behind. Let us all work hard to make sure we count all girls, because all girls count."





# Financial Statements

For the year ended 30 June 2016

**CLAN (Caring and Living as Neighbours) Inc**

CLAN (Caring And Living As Neighbours) Incorporated  
ABN 30 897 322 928

**WP Partners**

34 Main Road, Boolaroo NSW 2284  
Phone: (02) 4953 0070 | Email: [mail@wppartners.com.au](mailto:mail@wppartners.com.au)

# Financial Statements Ended June 2016

**CLAN (Caring And Living As Neighbours) Incorporated**  
**ABN 30 897 322 928**  
**Executive Committee's Report**  
**For the year ended 30 June 2016**

Your Executive Committee members submit the financial accounts of the CLAN (Caring And Living As Neighbours) Incorporated for the financial year ended 30 June 2016.

## **Executive Committee Members**

The names of Executive Committee members at the date of this report are:

Dr Kate Armstrong

Heidi Armstrong

Catherine Cole

Valerie Foley

## **Principal Activities**

The principal activities of the association during the financial year were: charitable organisation.

## **Significant Changes**

No significant change in the nature of these activities occurred during the year.

## **Operating Result**

The deficit from ordinary activities after providing for income tax amounted to

Year ended	Year ended
30 June 2016	30 June 2015
\$	\$
(43,194)	86,479

Signed in accordance with a resolution of the Members of the Executive Committee on:



Dr Kate Armstrong



Catherine Cole

# Financial Statements Ended June 2016

**CLAN (Caring And Living As Neighbours) Incorporated**  
**ABN 30 897 322 928**

**Independent Auditor's Report to the Members**

## **Report on the Financial Report**

We have audited the accompanying financial report, being a special purpose financial report, of CLAN (Caring And Living As Neighbours) Incorporated (the association), which comprises the Statement by Members of the Executive Committee, Income and Expenditure Statement, Balance Sheet, notes comprising a summary of significant accounting policies and other explanatory notes for the financial year ended 30 June 2016.

## **Executive Committee's Responsibility for the Financial Report**

The Executive Committee of CLAN (Caring And Living As Neighbours) Incorporated is responsible for the preparation and fair presentation of the financial report, and have determined that the basis of preparation described in Note 1 is appropriate to meet the requirements of the Associations Incorporation Act of New South Wales 2009 and is appropriate to meet the needs of the members. The Executive Committee's responsibilities also includes such internal control as the Executive Committee determine is necessary to enable the preparation and fair presentation of a financial report that is free from material misstatement, whether due to fraud or error.

## **Auditor's Responsibility**

Our responsibility is to express an opinion on the financial report based on our audit. We have conducted our audit in accordance with Australian Auditing Standards. Those Standards require that we comply with relevant ethical requirements relating to audit engagements and plan and perform the audit to obtain reasonable assurance whether the financial report is free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial report. The procedures selected depend on the auditor's judgement, including the assessment of the risks of material misstatement of the financial report, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the association's preparation and fair presentation of the financial report in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the association's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the Executive Committee, as well as evaluating the overall presentation of the financial report.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

## **Basis for Qualification of Auditor's Opinion**

It is not practical for the organisation to maintain an effective system of internal control over donations and fund raising activities until their initial entry in the accounting records, our audit in relation to donations and fund raising was limited to amounts recorded and the records provided. In addition it is not practical for the organisation to maintain an effective system of internal control over costs relating to travel in foreign countries where activities are undertaken due to the nature of the records in these countries until their initial entry in the accounting records, our audit in relation to these costs was limited to amounts recorded and the records provided.

## **Qualified Auditor's Opinion**

In our opinion, except for the effects of such adjustments, if any, as might have been determined to be necessary had the limitation discussed in the qualification paragraph not existed the financial report of the CLAN (Caring and Living As Neighbours) Incorporated presents fairly, the financial position of CLAN (Caring And Living As Neighbours) Incorporated as at 30 June 2016 and its financial performance for the year then ended in accordance with the accounting policies described in Note 1 to the financial statements, and the Associations Incorporation Act of New South Wales 2009.

# Financial Statements Ended June 2016

**CLAN (Caring And Living As Neighbours) Incorporated**  
**ABN 30 897 322 928**  
**Independent Auditor's Report to the Members**

## **Basis of Accounting and Restriction on Distribution**

Without modifying our opinion, we draw attention to Note 1 to the financial statements, which describes the basis of accounting. The financial report has been prepared to assist CLAN (Caring And Living As Neighbours) Incorporated to meet the requirements of the Associations Incorporation Act of New South Wales 2009. As a result, the financial report may not be suitable for another purpose.

Signed on :



---

Blair Andrew Powell, Registered Company Auditor

WP Partners

34 Main Road Boolaroo NSW 2284

# Financial Statements Ended June 2016

CLAN (Caring And Living As Neighbours) Incorporated  
ABN 30 897 322 928

Income and Expenditure Statement  
For the year ended 30 June 2016

	2016 \$	2015 \$
<b>Income</b>		
Donations and gifts		
Monetary		
- Corporate donations	220	7,000
- Personal donations	17,703	16,375
- Gofundraise	28	401
- Non-monetary	-	-
Bequests and legacies	-	-
Grants		
AusAID	-	-
Other Australian		
- Medtronics Grant	-	-
- DFAT	-	76,839
- Diabetes NSW	40,253	34,513
Other overseas		
- NCD Child Projects	-	41,911
- Neph Cure	-	10,391
- UNDPI/NGO	-	20,864
- Medtronics Grant	-	-
- Save the Children	-	-
- AZ/YHP Grant	-	-
-Pakistan Project	25,300	-
- Give2Asia	7,964	-
Investment income		
- Westpac interest	1,017	651
Other income		
- Members subscriptions	350	300
Revenue for International Political or Religious		
<b>Total income</b>	<b>92,836</b>	<b>209,245</b>
<b>Expenses</b>		
<b>Expenses</b>		
International Aid and Development Programs Expenditure		
- Guyana Fellowship		
- Overseas Travel/Accommodation	64,047	11,651

# Financial Statements Ended June 2016

CLAN (Caring And Living As Neighbours) Incorporated  
ABN 30 897 322 928

Income and Expenditure Statement  
For the year ended 30 June 2016

	2016 \$	2015 \$
- Funds to international programs		
- Programs support costs		
- Community education		
- Fundraising costs		
- Public		
- Government, multinational and private		
- Accountability and Administration		
- Accountancy	3,421	3,159
- Advertising and promotion	-	-
- ACFID fees	-	-
- Bank charges	175	403
- Computer expenses	176	150
- Conference fees	-	-
- DAP Vietnam Grant expenses	-	5,662
- Depreciation	389	796
- General expenses	90	110
- Gofundraise fee	-	300
- Insurance	2,700	2,595
- Legal fees	-	-
- NCD Child Conference	-	37,149
- UNDPI / NGO expenses	-	24,181
- Diabetes NSW expenses	35,431	31,902
- Pakistan Project	21,556	-
- Printing & stationery	5,829	3,010
- Subscriptions	1,819	1,626
- TeleConferences	215	72
- Travel, accom & conference	180	-
- Web design	-	-
- Non-Monetary Expenditure	-	-
Total International Aid and Development Programs		
<b>Expenditure</b>	<b>136,029</b>	<b>122,766</b>
International Political or Religious Adherence Promotion		
Programs Expenditure	-	-
Domestic Programs Expenditure	-	-
<b>Total expenses</b>	<b>136,029</b>	<b>122,766</b>
<b>Profit from ordinary activities before income tax</b>	<b>(43,194)</b>	<b>86,479</b>

# Financial Statements Ended June 2016

CLAN (Caring And Living As Neighbours) Incorporated  
ABN 30 897 322 928

Income and Expenditure Statement  
For the year ended 30 June 2016

	2016 \$	2015 \$
Income tax revenue relating to ordinary activities	-	-
<b>Net profit attributable to the association</b>	<b>(43,194)</b>	<b>86,479</b>
<b>Total changes in equity of the association</b>	<b>(43,194)</b>	<b>86,479</b>
Opening retained profits	110,355	23,876
Net profit attributable to the association	(43,194)	86,479
<b>Closing retained profits</b>	<b>67,162</b>	<b>110,355</b>

# Financial Statements Ended June 2016

CLAN (Caring And Living As Neighbours) Incorporated  
ABN 30 897 322 928

Balance Sheet as at 30 June 2016

	Note	2016	2015
		\$	\$
<b>Current Assets</b>			
Cash and cash equivalents	2	66,303	108,780
Trade and other receivables		477	804
Inventories		-	-
Assets held for sale		-	-
Other financial assets		-	-
<b>Total Current Assets</b>		<b>66,780</b>	<b>109,584</b>
<b>Non-Current Assets</b>			
Trade and other receivables		-	-
Other financial assets		-	-
Property, plant and equipment	3	382	771
Investment property		-	-
Intangibles		-	-
Other non-current assets		-	-
<b>Total Non-Current Assets</b>		<b>382</b>	<b>771</b>
<b>Total Assets</b>		<b>67,162</b>	<b>110,355</b>
<b>Current Liabilities</b>			
Trade and other payables		-	-
Borrowings		-	-
Current tax liabilities		-	-
Other financial liabilities		-	-
Provisions		-	-
Other		-	-
<b>Total Current Liabilities</b>		<b>-</b>	<b>-</b>
<b>Non-Current Liabilities</b>			
Borrowings		-	-
Other financial liabilities		-	-
Provisions		-	-
Other		-	-
<b>Total Non-Current Liabilities</b>		<b>-</b>	<b>-</b>
<b>Total Liabilities</b>		<b>-</b>	<b>-</b>
<b>Net Assets</b>		<b>67,162</b>	<b>110,355</b>
<b>Equity</b>			
Reserves		-	-
Retained profits		67,162	110,355
<b>Total Members' Funds</b>		<b>67,162</b>	<b>110,355</b>
<b>Total Members' Funds</b>		<b>67,162</b>	<b>110,355</b>



# Financial Statements Ended June 2016

CLAN (Caring And Living As Neighbours) Incorporated  
ABN 30 897 322 928

	Note	2016 \$	2015 \$
<b>Cash Flow From Operating Activities</b>			
Receipts from customers		211,972	211,972
Payments to Suppliers and employees		(121,970)	(121,970)
Interest received		651	651
<b>Net cash (used in) operating activities (note 2)</b>		<b>90,653</b>	<b>90,653</b>
Purchase of Plant & equipment		-	-
Net cash (used in) investing activities		-	-
<b>Net increase (decrease) in cash held</b>		<b>90,653</b>	<b>90,653</b>
Cash at the beginning of the year		18,127	18,127
<b>Cash at the end of the year (note 1)</b>		<b>108,780</b>	<b>108,780</b>

# Financial Statements Ended June 2016

CLAN (Caring And Living As Neighbours) Incorporated  
ABN 30 897 322 928

Notes to the Financial Statements  
For the year ended 30 June 2016

## Note 1: Summary of Significant Accounting Policies

This financial report is a special purpose financial report prepared in order to satisfy the financial reporting requirements of the Associations Incorporations Act of New South Wales. The Executive Committee has determined that the association is not a reporting entity.

The financial report has been prepared on an accruals basis and is based on historical costs and does not take into account changing money values or, except where specifically stated, current valuations of non-current assets.

The following significant accounting policies, which are consistent with the previous period unless otherwise stated, have been adopted in the preparation of this financial report.

### (a) Property, Plant and Equipment (PPE)

Leasehold improvements and office equipment are carried at cost less, where applicable, any accumulated depreciation.

The depreciable amount of all PPE is depreciated over the useful lives of the assets to the association commencing from the time the asset is held ready for use.

Leasehold improvements are amortised over the shorter of either the unexpired period of the lease or the estimated useful lives of the improvements.

### (b) Impairment of Assets

At the end of each reporting period, the entity reviews the carrying values of its tangible and intangible assets to determine whether there is any indication that those assets have been impaired. If such an indication exists, the recoverable amount of the asset, being the higher of the asset's fair value less costs to sell and value in use, is compared to the asset's carrying value. Any excess of the asset's carrying value over its recoverable amount is expensed to the income statement.

### (c) Cash and Cash Equivalents

Cash and cash equivalents include cash on hand, deposits held at call with banks, and other short-term highly liquid investments with original maturities of three months or less.

### (d) Revenue and Other Income

Revenue is measured at the fair value of the consideration received or receivable after taking into account any trade discounts and volume rebates allowed. For this purpose, deferred consideration is not discounted to present values when recognising revenue.

Interest revenue is recognised using the effective interest rate method, which for floating rate financial assets is the rate inherent in the instrument. Dividend revenue is recognised when the right to receive a dividend has been established.

Grant and donation income is recognised when the entity obtains control over the funds, which is generally at the time of receipt.

All revenue is stated net of the amount of goods and services tax (GST).

# Financial Statements Ended June 2016

**CLAN (Caring And Living As Neighbours) Incorporated**

**ABN 30 897 322 928**

**Notes to the Financial Statements**

**For the year ended 30 June 2016**

## **(e) Leases**

Leases of PPE, where substantially all the risks and benefits incidental to the ownership of the asset, but not the legal ownership, are transferred to the association, are classified as finance leases.

Finance leases are capitalised by recording an asset and a liability at the lower of the amounts equal to the fair value of the leased property or the present value of the minimum lease payments, including any guaranteed residual values. Lease payments are allocated between the reduction of the lease liability and the lease interest expense for that period.

Leased assets are depreciated on a straight line basis over the shorter of their estimated useful lives or the lease term. Lease payments for operating leases, where substantially all the risks and benefits remain with the lessor, are charged as expenses in the period in which they are incurred.

## **(f) Goods and Services Tax (GST)**

Revenues, expenses and assets are recognised net of the amount of GST, except where the amount of GST incurred is not recoverable from the Tax Office. In these circumstances, the GST is recognised as part of the cost of acquisition of the asset or as part of an item of the expense. Receivables and payables in the assets and liabilities statement are shown inclusive of GST.

# Financial Statements Ended June 2016

CLAN (Caring And Living As Neighbours) Incorporated  
ABN 30 897 322 928

Notes to the Financial Statements  
For the year ended 30 June 2016  
2016

2015

## Note 2: Cash assets

Bank accounts:

CLAN Donations	486	11,847
CLAN Fund	14,029	1,047
CLAN Fund Interest	51,789	95,886
	<b>66,303</b>	<b>108,781</b>

## Note 3: Property, Plant and Equipment

Leased plant and equipment:

- At cost	6,649	6,649
- Less: Accumulated amortisation	(6,267)	(5,878)
	382	771
	<b>382</b>	<b>771</b>

# Financial Statements Ended June 2016

**CLAN (Caring And Living As Neighbours) Incorporated**  
**ABN 30 897 322 928**

**Statement by Members of the Executive Committee**  
**For the year ended 30 June 2016**

The Executive Committee has determined that the association is not a reporting entity and that this special purpose financial report should be prepared in accordance with the accounting policies outlined in Note 1 to the financial statements.

In the opinion of the Executive Committee the Income and Expenditure Statement, Statement of Financial Position, and Notes to the Financial Statements:

1. Presents fairly the financial position of CLAN (Caring And Living As Neighbours) Incorporated as at 30 June 2016 and its performance for the year ended on that date.
2. At the date of this statement, there are reasonable grounds to believe that the association will be able to pay its debts as and when they fall due.

This statement is made in accordance with a resolution of the Executive Committee and is signed for and on behalf of the Executive Committee by:



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Dr Kate Armstrong

President



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Catherine Cole

Vice President

# Financial Statements Ended June 2016

**CLAN (Caring And Living As Neighbours) Incorporated  
ABN 30 897 322 928**

**Certificate by Member of the Executive Committee  
For the year ended 30 June 2016**

I, Dr Kate Armstrong of [ENTER ADDRESS], and I, Heidi Armstrong of [ENTER ADDRESS] certify that:

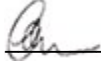
- a. We attended the annual general meeting of the association held on .
- b. The financial statements for the year ended 30 June 2016 were submitted to the members of the association at its annual general meeting.

Dated



Dr Kate Armstrong

Executive Committee Member



Catherine Cole

Vice President

The accompanying notes form part of these financial statements.



## Give to where it's needed.

Please help us to improve the quality of life for children living with chronic health conditions in countries where access to affordable medicine and quality healthcare isn't available. Where the chronic condition they have is often misdiagnosed, misunderstood, or hidden under layers of cultural stigma. Where existing health systems aren't able to provide the quality of care the child deserves.

*Every child has the right to good health care.*

## Please donate today.

[www.clanchildhealth.org/Donate](http://www.clanchildhealth.org/Donate)





## Contact Us

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