

**CLAN Inc Report
PFIZER AUSTRALIA GRANT 2016–2017**

**A Community–Centred Project for
CLIP (CAH Living in Pakistan)**

February 2018



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CLIP - which started as a dream - is now bridging the gap between patients and families, not only with their doctors, but also with fellow patients. Making them understand their illness (CAH) better, allowing them to make better informed decisions. Being more prepared and aware to take on the challenges that may lie ahead of them.

We might not yet be where we aim to be, but we are certainly not where we used to be.

The international community - namely CLAN and Pfizer Australia, to whom we are immensely thankful - had faith in us and provided us with support and opportunity.

With continued support and faith we hope to be better, making CLIP a model for future NCDs communities.

- Dr Salman Munir, CLIP (CAH Living In Pakistan) Founder and President

SECTION 1 – BACKGROUND TO THE CLIP PROJECT

This report details the goals, activities, outcomes and final recommendations emerging from a project managed by CLAN (Caring & Living As Neighbours), made possible by a generous grant from Pfizer Australia.

An introduction to CLAN

CLAN is an Australian-based Non-Government Organisation (NGO) and signatory to the ACFID (Australian Council for International Development) Code of Conduct. CLAN is approved by the Australian Taxation Office for OAGDS (Overseas Aid Gift Deductibility Status) and formally associated with the United Nations Department of Public Information (UNDPI) for NGOs.

Founded in 2004, CLAN is committed to equity for children living with chronic health conditions in low- and middle-income countries (LMICs). Our strategic framework for action utilises a rights-based, community development approach that maintains a community of children and families living with any particular chronic health condition as a visual hub for collaborative efforts around five key pillars:

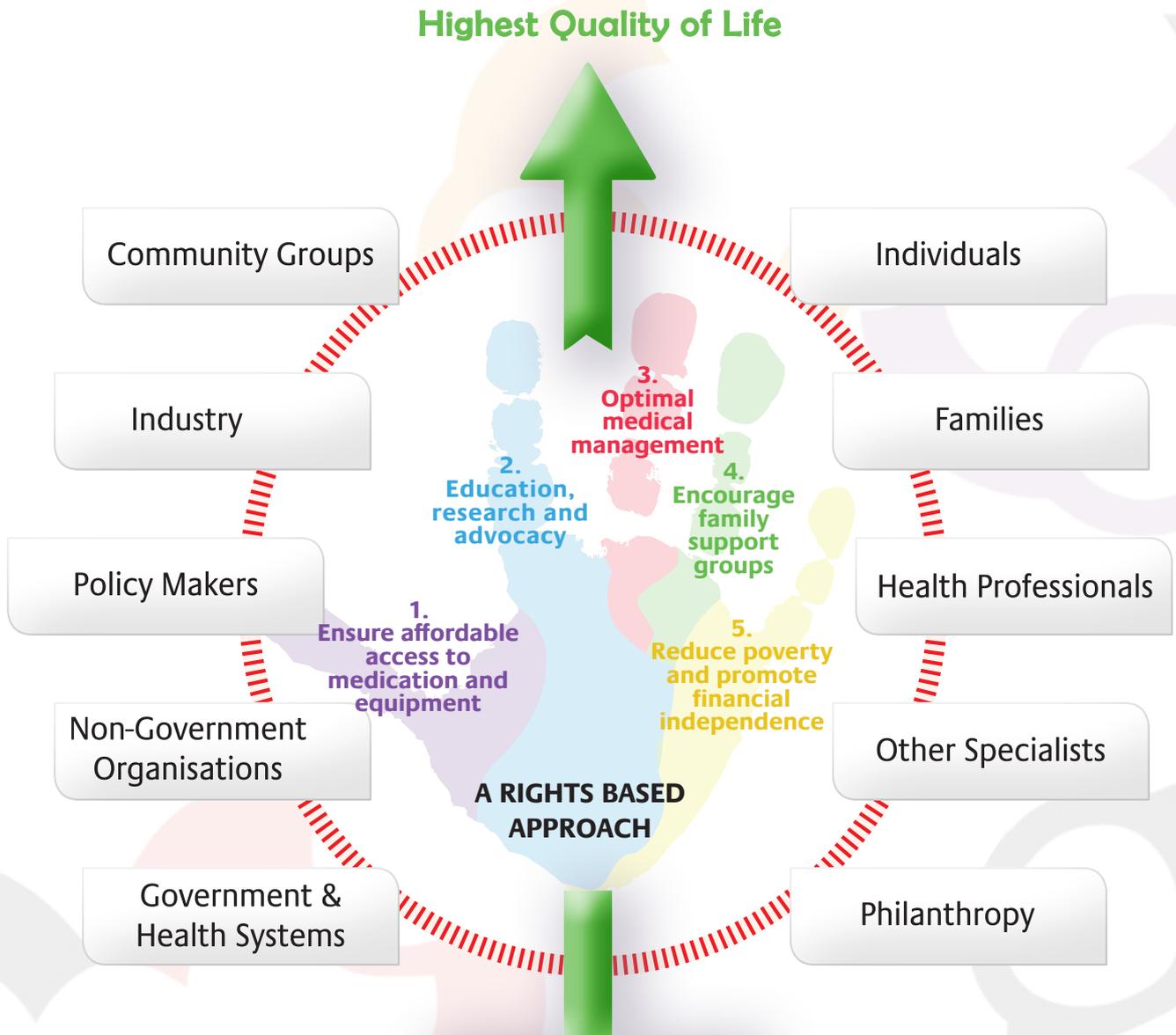
1. Affordable access to essential medicines and equipment
2. Education, research and advocacy
3. Optimal medical management
4. Encouragement of family support groups
5. Reducing financial burdens and promoting financial independence

CLAN works collaboratively with a range of partners, and was honoured to receive a grant from Pfizer Australia in early 2016 to support efforts for CLIP (CAH Living In Pakistan), the Congenital Adrenal Hyperplasia (CAH) Community of Pakistan.



CLAN's Strategic Framework for Action

CLAN is proving that by working together, it is possible to effect change on a global scale for children 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 and concerned global citizens.



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

Why focus on CAH?

Congenital Adrenal Hyperplasia (CAH) is an inherited condition requiring life-long access to hydrocortisone (tablets and injectable forms, such as Solu-Cortef) and fludrocortisone tablets for survival. These drugs are included on the World Health Organisation's Essential Medicines List for Children (WHO EMLc).

With early diagnosis and appropriate treatment, children living with CAH can expect to enjoy a high quality of life and normal life expectancy. This is most usually achieved for children in high-income countries, where mortality associated with CAH is very rare. Regrettably however, in many LMICs around the world, children with CAH frequently experience inequitable and entirely preventable morbidity and mortality.

A partnership for CLIP (the CAH Community of Pakistan) with NICH

CLAN (Caring & Living As Neighbours) has been partnering with doctors and members of CLIP (CAH Living In Pakistan, the national CAH Community) attending the National Institute of Child Health (NICH) for care in Karachi, Pakistan since 2007. NICH is the largest government charity children's hospital in Pakistan. A 500 bed tertiary institution, NICH provides all care free of charge and provides quality health care to the most vulnerable children of Sindh Province (population 20 million).

In July 2015 CLAN travelled to NICH and attended the launch of the new national Society of Pediatric Endocrinology & Diabetes (SPED) in Pakistan. A snapshot survey of doctors at the launch of SPED indicated the mortality and morbidity associated with Congenital Adrenal Hyperplasia (CAH) in Pakistan continues to be unacceptably high, and as a result CLAN committed to fast-tracking our partnerships and efforts for children living with CAH in Pakistan.

In 2015 it was not known exactly how many children were living with CAH in Pakistan, however current estimates placed the number at around 500 children nationally. This number took into account the high mortality historically associated with CAH in Pakistan, particularly in light of the challenges associated with affordable, reliable access to essential medicines and quality care.



CLIP Project proposal to Pfizer Australia

CLAN approached Pfizer Australia in 2015, requesting a longer-term partnership that would commence with a focus on CLIP (the CAH Community of Pakistan) in 2016-17, with a view to extending collaborative efforts around CLAN's strategic framework for action to other CAH communities internationally in the future.

The intention of the proposal was to establish a strong model for partnership that could be used to extend the partnership between CLAN and Pfizer into other priority countries into the future.

Utilising CLAN's five pillars, an assessment was conducted of the situation facing the CAH Community of Pakistan, and urgent needs and possible solutions were identified (please see Appendix 1). A program logic framework was subsequently developed (please see Appendix 2) and a proposal was submitted to Pfizer Australia in 2015.

Pfizer Australia generously donated a grant of AUS25,000 to CLAN in early 2016 and this final report details the outcomes of the grant.

SECTION 2 – CLIP PROJECT OVERVIEW

The ultimate goal of the CLIP Project is that children living with CAH around the world might enjoy equitable health outcomes and quality of life.

The short-term (0-2 years) outcomes of the CLIP Project were:

- Outcome 1** Increased use of quality shared indicators to track reductions in preventable morbidity and mortality for children living with CAH in Pakistan
- Outcome 2** Quality educational resources available in Urdu and promoted by SPED to facilitate education of families, communities and Health Care Professionals (HCPs)
- Outcome 3** CLIP membership increases and increased participation at Club meetings
- Outcome 4** NICH and SPED staff appropriately trained and confident to support families to care for children living with CAH.

The medium-term (2-5 years) outcomes of the project were:

- Outcome 1** Essential medicines, equipment and education necessary for optimal management of CAH affordably available to all CLIP members in Pakistan
- Outcome 2** Sustainable funding identified for CLIP
- Outcome 3** Quitable school attendance rates achieved for children with CAH
- Outcome 4** The parents of EVERY child diagnosed and living with CAH in Pakistan has access to the medicine, equipment, education and support necessary to manage sick day care.

The desired long-term (5-10 years) outcome of the CLIP Project was for:

The CAH Community of Pakistan to be recognised as a benchmark community development model for autonomous and collaborative multisectoral action to benefit children living with CAH and other Non-Communicable Diseases (NCDs) in the Asia Pacific region.

Key activities agreed for the CLIP Project emerged from the community needs assessment (please see Table 1) utilising CLAN's five pillars and were as follows:

1. Identification of barriers to (and solutions for) affordable access to hydrocortisone (tablets and injection) and fludrocortisone tablets in Pakistan explored
2. Online platforms supporting community development for CLIP
3. Translated Urdu CAH Peptalk made available online
4. Translation of Hsu & Rivkees book into Urdu
5. CAH register development and implementation nationally
6. G Warne booklet (Urdu) disseminated nationally via SPED (online and paper)
7. Regular CLIP meetings
8. SPED Forums and NCD / NCD Child Symposiums / educational support for health professionals
9. Sustainable funding solutions explored
10. Child Rights Flyer for CAH community in Urdu
11. Mobile phone app development.

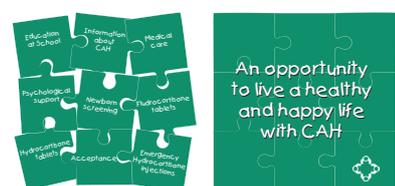
What are the Rights of the Child Living with Congenital Adrenal Hyperplasia (CAH)?

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 (UNCRC) 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.

CAH is the most common adrenal condition of childhood. As a child living with CAH, 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 CAH and other chronic health conditions in low- and middle-income countries ask for help with five key action areas (CLAN's Five Pillars). Fortunately, UNCRC recognises these needs as the rights of children.



What do Children Living with CAH Need to Live a Happy and Healthy Life?



EVERY child living with CAH should have affordable access to hydrocortisone and fludrocortisone tablets and hydrocortisone injections. These drugs are on the WHO Essential Medicine List for children.



All families should have access to information on CAH in their own language and to a trained health professional. Research on CAH is also important.



Children living with CAH must visit their doctor for regular checkups. They also need access to emergency treatment on sick days.



The chance to connect with other people who are living with CAH for support and encouragement helps children and families learn and grow as a community.



Every child with CAH should enjoy a fulfilling life, free from social stigma and isolation. Every child with CAH should attend school and have the opportunity to play sports.



CAH can be easily diagnosed with heel-prick testing of newborn babies. The test is cheap, safe, accurate and saves lives by diagnosing CAH early.

Partnerships were identified by CLAN as vitally important to the success of the CLIP Project. Key partners, opinion leaders and stakeholders engaged in this project included:

- CLIP (CAH Living in Pakistan) members
- Pfizer Australia and Pfizer Pakistan
- NICH (National Institute of Child Health) in Pakistan
- CAH PepTalk – led by Irene Mitchelhill (CAH Nurse Specialist)
- APPEP (Asia Pacific Pediatric Endocrinology Society) – Executive members, notably: Prof Maria Craig, Dr Paul Hofman (Current President), Prof Craig Munns (Treasurer), Dr Suttipong Wacharasindhu (incoming President), Dr Reiko Horikawa (Immediate Past President) and Aman Pulungan.
- APEG (Australasian Pediatric Endocrinology Group)
- SPED (Society of Pediatric Endocrinology and Diabetes of Pakistan)
- CAHSGA (CAH Support Group Australia)
- CHW (Children's Hospital Westmead)
- Wirrim Media
- Kudu & Mimi
- Australian High Commission
- NCD Child – a global coalition founded by CLAN; now chaired by Executive Director, Dr Mychelle Farmer of the American Academy of Pediatrics
- EWEC (Every Woman Every Child) Movement of the UN Secretary General
- GPED (Global Paediatric Endocrinology and Diabetes) - Current Secretary General, Dr JP Chanoine.
- AWS (Atfaal Welfare Society)

SECTION 3 – REPORT ON CLIP PROJECT ACTIVITIES

The activities identified as key priorities for the CLIP Project emerged from the community needs assessment (Appendix 1) that was informed by CLAN's five pillars. Progress on and lessons learned relating to these activities were as follows:

Proposed Activities	Outputs	Lessons Learned
<p>1 Identification of barriers to (and solutions for) affordable access to hydrocortisone (tablets and injection) and fludrocortisone tablets in Pakistan explored</p>	<p>Strategic champions led extensive consultation with broad range of stakeholders to better understand barriers and potential solutions</p> <p>Meeting held with Pfizer Pakistan to understand local situation (Solu-Cortef no longer registered for sale locally)</p> <p>CLIP meeting used to support national advocacy efforts and raise awareness of the need for children living with CAH in Pakistan to have access to hc and fc tablets</p> <p>Media articles helped to raise national awareness</p> <p>Education of families on use of medicines integrated in CLIP meetings</p>	<p>Barriers to access to essential medicines required for the CAH Community are significant</p> <p>Lack of access to essential medicines is a major barrier to community growth and well-being</p> <p>Ongoing community efforts (such as CLIP meetings promoted in the national media) and the high-level, strategic support of SPED to advocate nationally for change are essential to efforts to drive change</p> <p>International support of advocacy efforts is very powerful</p> <p>Involvement of partners in industry offers real hope for the identification of sustainable business solutions</p>



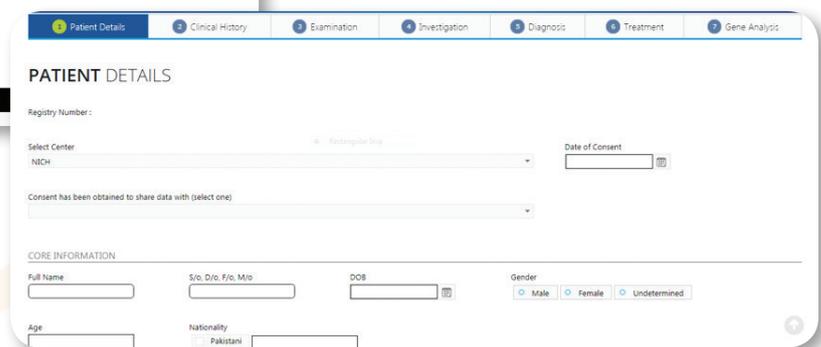
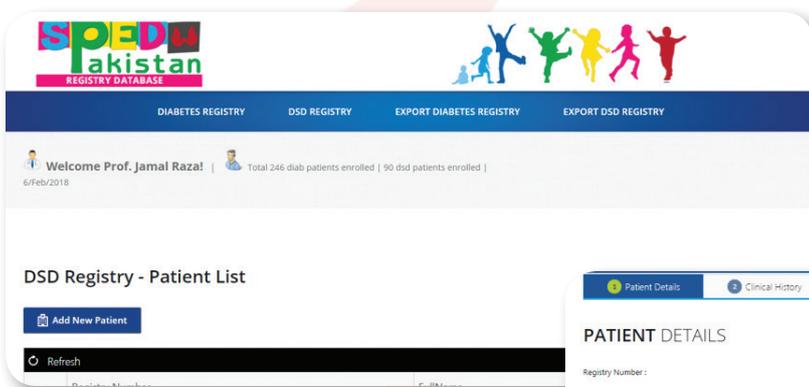
<http://dailytimes.com.pk/sindh/12-Aug-17/nich-director-appeals-to-the-govt-to-register-cah-patients-medicines>

Proposed Activities	Outputs	Lessons Learned
<p>2 Translated Urdu CAH Peptalk made available online</p>	<p>CAH PepTalk translation in final stages of edit in preparation to go online</p> <p>Information sheet on use of Solu-Cortef translated into Urdu</p>	<p>Translation of educational resource into Urdu is extremely complex. Very few people can type Urdu. Support from APMA (Australia Pakistan Medical Association) and volunteers in Australia has been invaluable</p>

Proposed Activities	Outputs	Lessons Learned
3 Translation of Hsu & Rivkees book into Urdu	<p>Translation of this 200page book into Urdu was deemed not feasible at an early stage of the project due to the com-plexity of translating re-sources into Urdu</p> <p>The budget allocated to this translation was in-stead diverted to sup-port the development of the mobile phone app and CAH register</p>	<p>Translation of the CAH PepTalk into Urdu was identified by local partners as the higher priority educational resource (available as video and would therefore be available for non-literate families)</p> <p>Development of the CAH register and mobile phone app were identified as hugely important for capacity building and could support regional efforts into the future (over-arching goals of the project)</p>
4 G Warne booklet (Urdu) disseminated nationally via SPED (online and paper)	<p>Completed</p> <p>Distribution nationally is supported through SPED network</p>	Invaluable educational resource now able to be shared with all new and existing CAH families across Pakistan



Proposed Activities	Outputs	Lessons Learned
5 CAH register development and implementation nationally	<p>Completed</p> <p>Register is accessible online and available nationally through SPED</p> <p>Ongoing maintenance of register is supported by SPED</p> <p>At end 2017 approximately 100 children with CAH have been entered on to the register</p>	The register is available to be shared with Australia and other countries, and offers enormous opportunities to strengthen international research into CAH



Proposed Activities	Outputs	Lessons Learned
<p>6 SPED Forums / NCD Child Symposiums held / educational support for health professionals</p>	<p>Achievements of CLIP Project shared nationally through SPED network</p> <p>Mobile phone app and CAH register shared with SPED members to promote use across Pakistan</p> <p>NCD Child Symposium conducted in March 2017 to raise awareness of challenges of children living with NCDs and disability in Pakistan; supported by Pakistan Paediatric Association and attended by UN representatives</p> <p>Dr Rabia Baloch (Community Development Officer supporting CLIP Project travelled to Australia in 2017 to attend the World Public Health Congress and presented on CLIP project)</p>	<p>Through support of SPED, development and sharing nationally of the mobile phone app was considered key to promoting capacity building in paediatric endocrinology across Pakistan. The mobile app is now being shared regionally through CLAN's partnership with APPES</p>



Proposed Activities	Outputs	Lessons Learned
<p>7 Child Rights Flyer for CAH community in Urdu</p>	<p>Launch of CAH Rights Flyer in February 2017</p> <p>Attendance by member of CLAN at WHO Seminar on Human Rights and NCDs, and CAH flyer shared with WHO and others</p>	<p>The rights flyer has been shared internationally and supported advocacy efforts of the international CAH community</p> <p>Translated into French, Spanish, Swahili, Bahasa Indonesian and Vietnamese</p>



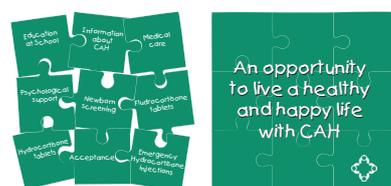
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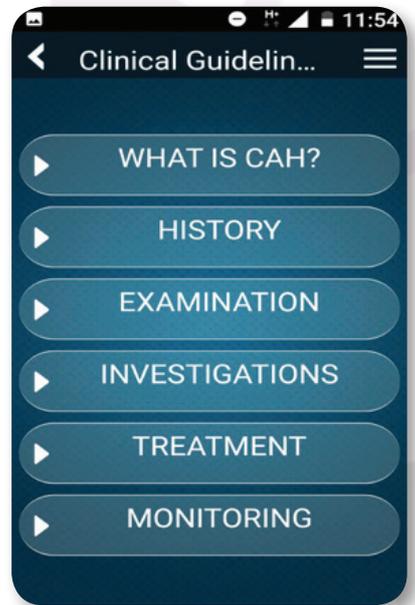
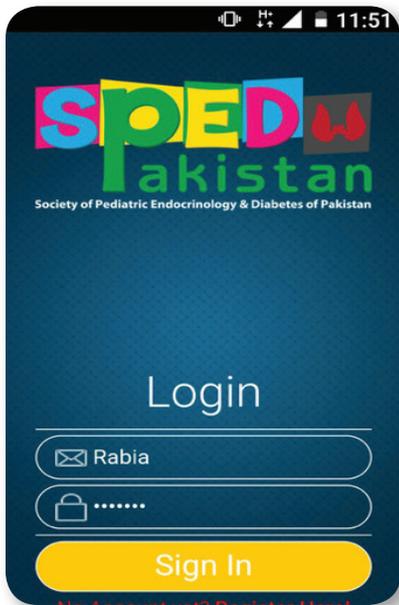
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An opportunity to live a healthy and happy life with CAH



Proposed Activities	Outputs	Lessons Learned
8 Mobile phone app development	<p>Completed</p> <p>Now available for android phones and will be available for apple phones in 2018</p> <p>Available and shared nationally through SPED network</p> <p>Available to all paediatricians and paediatric endocrinologists in Pakistan to help promote management of CAH and other endocrine conditions</p>	<p>CLAN working with APPES to explore possibility of sharing app regionally</p> <p>Evaluation of mobile phone app in progress</p>



Proposed Activities	Outputs	Lessons Learned
9 Online platforms supporting community development for CLIP	<p>Mobile phone app and CAH register available</p> <p>CLIP Facebook page operational</p> <p>CAH PepTalk will be available online in Urdu in early 2018</p>	<p>CAH register and app being shared regionally</p> <p>Facebook and text messaging systems used to communicate with CLIP members</p> <p>Few CLIP members have smart phones</p> <p>Literacy is an issue for most poor families</p>



Proposed Activities	Outputs	Lessons Learned
10 Regular CLIP meetings	<p>CAH Community of Pakistan met regularly and supported by Community Development Office</p> <p>CLIP meeting report in newspaper assisted advocacy efforts to promote access to medicines</p>	<p>Role of Community Development Officer vitally important in supporting ongoing efforts for CLIP</p> <p>SPED a powerful network to promote action for CLIP</p> <p>The President of CLIP is now recognised internationally as representative of CAH Community in Pakistan, and works collaboratively with CARES (the US CAH network), giving CLIP additional avenues for support and information</p>



Proposed Activities	Outputs	Lessons Learned
<p>11 Sustainable funding solutions explored so work of Community Development Officer can continue</p>	<p>Partnership with Australia Pakistan Medical Association (APMA) explored and offers fantastic ongoing potential for support</p> <p>Video promoting CLIP Project and telling the story of CLAN's partnership with Pfizer produced. This will assist with raising awareness and building future partnerships to promote sustainability</p> <p>Partnership explored with Kudu & Mimi, an Australian organisation committed to helping CAH Communities access essential medicines</p> <p>CDO introduced to CAH Support Group Australia</p>	<p>New partnership with APMA offers potential for ongoing support of CDO role</p>



SECTION 4 - REPORT ON CLIP PROJECT OUTCOMES

4.1 Short-term outcomes

Achievements relating to the short-term outcomes of the CLIP Project are as follows:

Short-term outcomes	Status at end of 2017
Outcome 1 Increased use of quality shared indicators to track reductions in preventable morbidity and mortality for children living with CAH in Pakistan	Nationally available CAH register is now promoted through SPED network and allows doctors across Pakistan to enter data on CAH patients Approximately 100 children are now on the register CAH register assisting with tracking prevalence and incidence data Ongoing donations of medicines are only given to children who are on the CAH register, and this continues to strengthen opportunities for data use and analysis (drugs are given free of charge to those on the database) Register is being promoted through CLAN-APPES partnership, for use in other countries Opportunity to use register in Australia, with initiation of Newborn Screening (NBS) for CAH due for implementation in 2018
Outcome 2 Quality educational resources available in Urdu and promoted by SPED to facilitate education of families, communities and HCPs	Quality translation of an online video educational resource on CAH in Urdu are nearing completion and will be available to doctors and families internationally (www.cahpeptalk.com) Pfizer Solu-Cortef information sheets available in Urdu A mobile phone app supporting health professionals in optimal management of CAH is now available to all doctors in Pakistan, and will be promoted regionally through CLAN-APPES network
Outcome 3 CLIP membership increases and increased participation at Club meetings	Regular CLIP meetings enable CLIP members to connect and learn more about CAH, providing a common platform to discuss issues and concerns CLIP meeting promoted in national newspaper of Pakistan Mobile phone app to be made available to CLIP members in 2018 CLIP Facebook account operational Community Development Officer available to support CLIP members
Outcome 4 NICH and SPED staff appropriately trained and confident to support families to care for children living with CAH	Mobile phone app promoted via SPED network and building capacity of health professionals nationally G Warne booklet in Urdu shared through SPED network and given free of charge to all CAH families in Pakistan

4.2 Medium-term outcomes

Achievements relating to the medium-term outcomes of the CLIP Project include:

Medium-term outcomes	Activities
<p>Outcome 1</p> <p>Essential medicines, equipment and education necessary for optimal management of CAH affordably available to all CLIP members in Pakistan</p>	<p>Short-term humanitarian systems are in place to assist all CLIP members to access the essential medicines they need, whilst longer-term solutions (registration of the drugs and inclusion of drugs in the national insurance scheme) are explored</p> <p>All CLIP members are informed about the importance of knowing how to inject hydrocortisone to manage adrenal crises and sick days</p> <p>As at late 2017, NICH is working with Ministry of Health officials to progress the registration of hydrocortisone and fludrocortisone tablets for local sale, with a short-term humanitarian aid program in place as an interim solution</p>
<p>Outcome 2</p> <p>Sustainable funding identified for CLIP</p>	<p>CLAN's emerging partnership with APMA (the Australia Pakistan Medical Association) offers optimism for the longer term prospects of community development approaches at NICH</p> <p>Advocacy video produced to share story of work to support CLIP Community in Pakistan and share with potential partners</p>
<p>Outcome 3</p> <p>Equitable school attendance rates achieved for children with CAH</p>	<p>School attendance and achievements are promoted extensively at CLIP meetings and in the mobile phone app</p> <p>The new CAH register will enable doctors to more effectively track morbidity, mortality and health outcomes relating to CAH in Pakistan</p>
<p>Outcome 4</p> <p>The parents of EVERY child diagnosed and living with CAH in Pakistan has access to the medicine, equipment, education and support necessary to manage sick day care</p>	<p>The CAH register and mobile phone app offer new ways to ensure consistent, high quality approaches to the management of CAH in Pakistan</p> <p>CLIP Facebook offers a new way for families to connect and learn about CAH</p> <p>The SPED network promotes optimal management of CAH in Pakistan and ongoing training of health professionals</p>

SECTION 5 – GENERAL REFLECTIONS

5.1 Situational analysis

General reflections relating to the strengths, challenges, opportunities and risks relevant to the CLIP Project are as follows:

STRENGTHS	CHALLENGES
<p>Role of Community Development Officer was vital to success of the project</p> <p>Harnessing new technology (CAH register and mobile phone app) offers powerful platforms for sustainable change</p> <p>Wide range of partnerships was strength of project (academia, private sector, IT, media etc)</p> <p>Emerging partnership between CLAN and APMA (Australia Pakistan Medical Association) offers strong prospects for longer term sustainability</p> <p>Profile of CLIP and President of CLIP continues to grow internationally</p>	<p>Translation of educational resources into Urdu was much harder than anticipated and required significant consultation with local partners to determine most appropriate solutions</p> <p>Role out of the mobile phone app to families has been limited to date because few families can afford smart phones</p> <p>Ongoing funding to ensure Community Development Officer role continues is a key priority for CLAN, CLIP and NICH</p> <p>Access to essential medicines continues to be a challenge for CLIP</p>
OPPORTUNITIES	RISKS
<p>Dissemination of the CAH register and mobile phone across the Asia Pacific region offers the chance for children in other countries to benefit from the work of this project. Implementation of the CAH Register in Australia (with the rollout of Newborn Screening) offers the chance for strong data collection on CAH in Australia for the first time</p> <p>As more and more families in Pakistan can afford smart phones, the mobile app will be increasingly useful to families as well as health professionals</p> <p>Involvement of key partners in ongoing advocacy efforts to secure local registration of essential medicines and affordable access is easier as range of partners involved grows</p> <p>Translation of the Hsu and Rivkees book on CAH into Urdu is a worthwhile longer term goal</p>	<p>Comprehensive community development approach to supporting children living with CAH in LMICs can be complex, and the importance of community events (such as CLIP meetings) can be overlooked. It is essential to maintain a person and community centred approach</p> <p>Funders can be reluctant to invest in wages for Community Development Officers, and yet this role has emerged as a critical success factor to the CLIP Project</p> <p>Access to essential medicines for families continues to present major challenges and burdens. Sustainable, long-term solutions must be achieved before the CLIP members can be assured of a strong future</p>

CLIP aims to empower patients and families living with CAH. The outcomes gained from this project compel us to achieve sustainability and strengthen the community. I hold high levels of gratitude for Pfizer Australia and CLAN for providing us the opportunity to develop a community for CAH. We further aim to exhibit CLIP as a model for community development of other NCDs

– Dr Rabia Baloch, CLAN Community Development Officer

5.2 Review of processes

The program logic framework provided a mechanism for regular evaluation and monitoring of progress throughout the CLIP Project.

CLAN members in Australia were in regular email, skype and phone contact with Dr Rabia Baloch (CLAN's Community Development Officer, based at NICH) and Prof Jamal Raza (Director of NICH). Whilst the budget did not include monies for formal external evaluation, regular informal feedback mechanisms, GANTT timeline reviews, budget updates and more structured project "CLIP Project Health Checks" were conducted jointly by the teams at CLAN and NICH to ensure the project progressed smoothly.

Specific evaluations and reports of different activities were completed where relevant. For example, a formal evaluation of the CAH Rights Flyer was conducted; a formal report was completed on the NCD Child Symposium and CLIP meetings; and development and launch of the CAH Registers and mobile phone app was conducted in collaboration with national and international experts through the SPED and APPES networks.

Where feasible, SMART (Specific, Measurable, Achievable, Relevant and Time bound) indicators were identified to track progress on the project. For example, indicators include number of children entered into the CAH Register; social media measures of engagement for the CAH Flyer launch; numbers of families attending the CLIP meetings; number of media articles emerging from advocacy efforts.

5.3 Review of budget

A summary of the budget is provided in Appendix 8.3.

The only adjustment to the proposed budget for this project was the decision not to translate the Hsu and Rivkees educational resource into Urdu. The rationale for this decision was twofold:

- Firstly, the translation process was unexpectedly onerous, in the main due to the very limited number of people who are able to type Urdu directly into a Word or other electronic document
- Secondly, the printed versions of the G Warne booklet were very well received amongst CLIP members, and overall low literacy levels meant the cost benefit of translating a larger resource into Urdu was considered a less urgent priority for the CLIP community at this time.

In consultation with local partners and after notifying Pfizer of the change in project plans it was determined the funds for the translation would be re-allocated to the development and implementation of a CAH register (to increase the capacity for future research – pillar 2) and a mobile phone app (to support local health professionals optimally care for children with CAH – pillar 3). Both of these activities were completed in full.

SECTION 6 – RECOMMENDATIONS

Overall, the CLIP Project was highly effective, and achieved all the short-term outcomes proposed in the over-arching program logic framework.

Ongoing efforts will be required if the medium and longer-term outcomes are to be met in entirety. To this end, four specific recommendations are offered:

1) Expansion of CAH Register

There are substantial opportunities to strengthen CLIP Community capacity and well-being by ensuring rollout of the CAH Register succeeds nationally. In addition, there are exciting opportunities to share the CAH Register developed as a result of the CLIP Project with other CAH Communities and paediatric endocrinologists in the Asia Pacific region. CLAN is keen to explore opportunities to expand the register regionally in partnership with Pfizer Australia and internationally. CLAN's partnership with APPE (Asia Pacific Pediatric Endocrinology Society) offers a platform for exploring this further.

One specific and immediate opportunity that has already been identified with regards expansion of use for the CAH Register developed in the CLIP Project is the CAH Community of Australia. Newborn Screening (NBS) for CAH has recently been approved by the Australian government. Use of a CAH register in Australia would offer a strategic opportunity to ensure every child and family diagnosed with CAH in Australia was offered the education and support needed to manage sick days and use Solu-cortef during emergencies, and this is an exciting opportunity that CLAN, APPE and APEG would be keen to explore with Pfizer Australia.

2) Expansion of mobile phone app

The mobile phone app developed as a result of the CLIP Project offers an innovative approach to the education of individuals living with CAH, families and health professionals alike. Uptake of the mobile phone app is currently limited to Pakistani medical doctors who are members of SPED (the Society of Pediatric Endocrinology and Diabetes). There are opportunities to expand use beyond Pakistan, and CLAN would be keen to explore this with Pfizer. Again, CLAN's partnership with APPE (Asia Pacific Pediatric Endocrinology Society) offers a platform for exploring this further, and the 2018 APPE Conference would be a specific platform to consider for the launch of such an initiative.

3) Continuation of Community Development Officer role

The role of the Community Development Officer (CDO) was instrumental to the success of the CLIP Project. Recruited by NICH Executive and reporting directly to CLAN and NICH Executive jointly, this role was vital to the day to day running of the project and support given to CLIP. Sustainable funding solutions to support continuation of this role are being explored currently in Pakistan, and CLAN would welcome the opportunity to expand the CDO role not just in Pakistan (through a train the trainer scheme), but in partnership with CAH Communities in other countries we partner with. CLAN has recently identified a new partnership with APMA (the Australia Pakistan Medical Association) and there are exciting capacity building initiatives being explored locally in Pakistan by NICH and APMA to build the capacity of NICH to continue funding the role of the CDO into the future. CLAN would be keen to continue supporting the CDO role in Pakistan until this is secured, as well as role out the model in other countries where there was interest.

4) Ongoing partnerships needed to explore solutions relating to access to medicines

Affordable access to hydrocortisone tablets and fludrocortisone tablets in Pakistan is an ongoing concern and humanitarian emergency. Registration and local supply of both drugs in Pakistan is urgently needed, and CLAN would welcome the opportunity to engage with Pfizer (both in Australia and internationally) to learn more about potential solutions to this complex issue. CLAN does not seek drug donations, but rather an intellectual partnership to identify sustainable and mutually beneficial business solutions that will aid efforts to improve access to hydrocortisone (both tablets and for injection) across the Asia Pacific region.

SECTION 7 – CONCLUSION

The impact of the CLIP Project has already been very significant:

- Comprehensive efforts are underway to solve the ongoing challenges relating to access to essential medicines for CLIP
- New and high quality educational resources have been made available free of charge to every family living with CAH in Pakistan
- Innovative solutions that will promote ongoing education and research have been identified, developed and launched
- Medical professionals have access to a mobile phone app that enhances their capacity to optimize medical management of CAH across Pakistan
- The CAH Community of Pakistan has been strengthened and encouraged
- Sustainable funding solutions are being explored to support ongoing efforts for CLIP.

Significant short and medium term outcomes were achieved by the CLIP Project, and indeed there are early indications the activities and outputs associated with the CLIP Project, for the benefit of the CAH Community of Pakistan, will achieve the longer term goal of the project: to highlight the power of a community development approach to promote autonomous and collaborative multisectoral action with the potential to benefit children living with CAH and other NCDs in the Asia Pacific region.

In addition to the outcomes that were identified in the planning of this project, other unexpected and exciting outcomes have been achieved as a result of the CLIP Project. For instance, support was able to be given to other NCD Communities indirectly, with a range of benefits arising for the Diabetes, Osteogenesis Imperfecta, Hypothyroidism and Polio communities emerging as a direct result of the CLIP Project, and efforts are underway to translate the learnings of CLIP to these communities into the future.

CLAN wishes to thank all partners involved for their generous contributions. There are exciting opportunities moving forward to translate key learnings and achievements from the CLIP Project in Pakistan to other CAH and NCD communities across the Asia Pacific region, and CLAN is hopeful of working further with Pfizer Australia and other key partners to continue driving change for some of our region's most vulnerable children.

SECTION 8 – APPENDICES

Appendix 1 Community focused approach to project planning using CLAN’s Strategic Framework for Action

Appendix 2 Program logic framework

Appendix 3 Budget

Appendix 1 Community focused approach to project planning using CLAN's Strategic Framework for Action

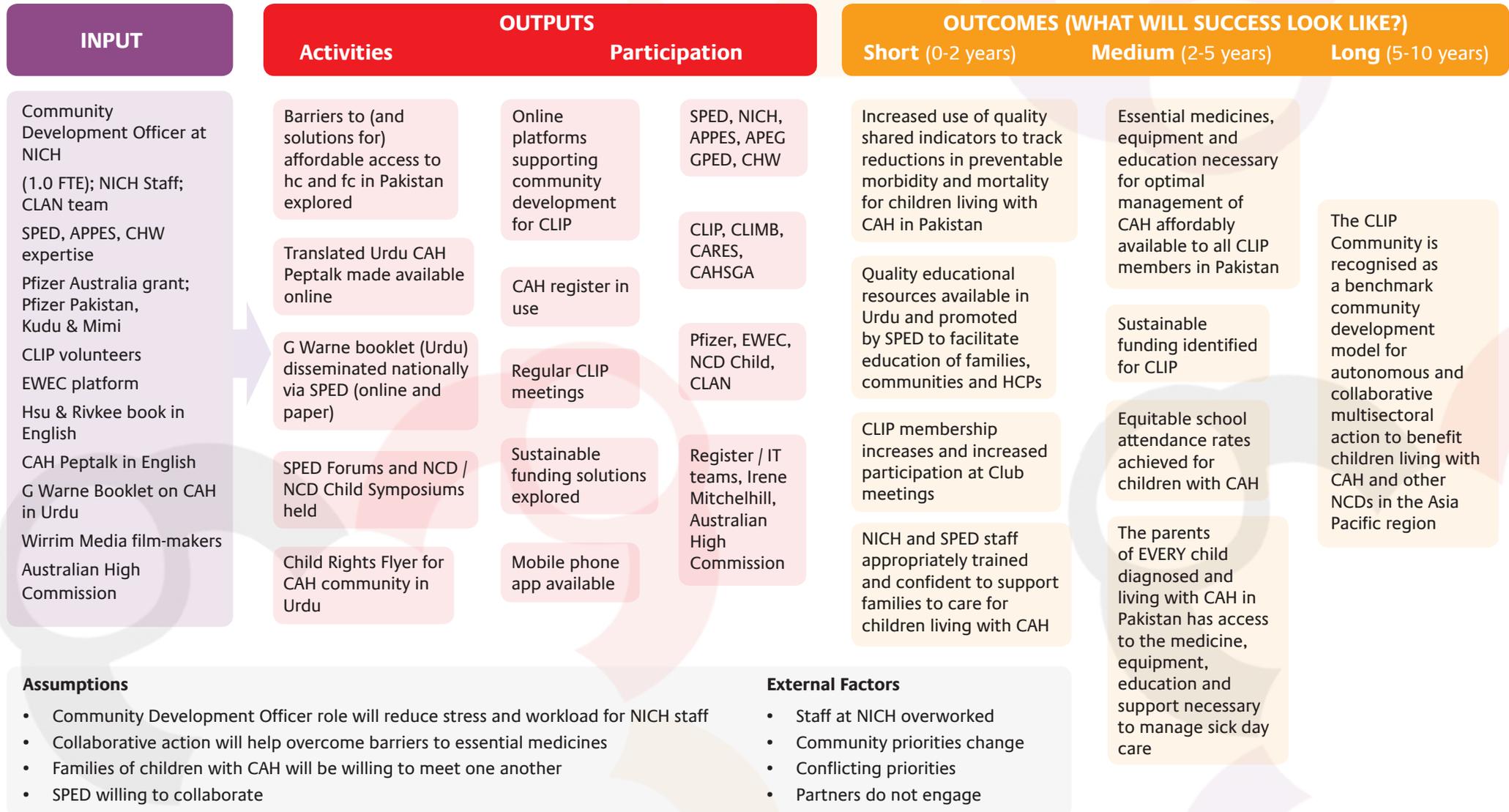
Pillar	Current Situation	What's Needed	Proposed Solutions
1. Affordable access to medicine and equipment	<p>Although hydrocortisone tablets are included on the WHO's Essential Medicines List for Children, they are not yet registered or legally available for sale in Pakistan.</p> <p>Pfizer operates in Pakistan and also manufactures hydrocortisone tablets internationally.</p> <p>Support local efforts to ensure all CAH families have local access to hydrocortisone injection kits in Pakistan</p>	<p>Assistance is required by partners with local expertise, knowledge and experience to clarify the current barriers to local registration of hydrocortisone tablets for CLIP in Pakistan, and support local efforts to secure local registration and supply of hydrocortisone tablets.</p> <p>Although Solu-Cortef is registered and available in Pakistan, no families currently have access to kits in their own home and are reliant on travel to hospital for access. Use patient register to ensure all families are offered kit and training.</p>	1. Identification of barriers to (and solutions for) affordable access to hydrocortisone (tablets and injection) and fludrocortisone tablets in Pakistan explored.
2. Education, research and advocacy	<p>Education of all families remains a key priority if quality of life for children living with CAH is to be improved. The only educational resource currently available on CAH in Pakistan is Garry Warne's booklet "Your Child With CAH" (translated by CLAN).</p> <p>Education of health professionals, in collaboration with SPED, APPES and others is required.</p> <p>International awareness into the plight of children living with CAH in low- and middle-income countries is still needed</p>	<p>Translation of key educational resources into Urdu is still required.</p> <p>Annual CLIP meeting facilitated educational of large numbers of families.</p> <p>Development of educational resources for use by staff and CLIP to promote sick day management and use of injection kits.</p> <p>Health professionals are needed to run CLIP meetings. Attendance at international educational sessions is key to building national expertise and capacity.</p> <p>Attendance by health professionals at international conferences to present local findings will help build awareness internationally of need for action</p>	<ol style="list-style-type: none"> Translated Urdu CAH Peptalk made available online Translation of Hsu & Rivkees book into Urdu CAH register development and implementation nationally G Warne booklet (Urdu) disseminated nationally via SPED (online and paper) SPED Forums / NCD Child Symposiums held / educational support for health professionals Child Rights Flyer for CAH community in Urdu
3. Optimal medical management	<p>The importance of injections of Solu-Cortef on sick day and need for availability locally is not yet a major focus for CLIP</p>	<p>Support for development of local guidelines and awareness.</p> <p>Educational sessions for health professionals</p>	8. Mobile phone app development

Pillar	Current Situation	What's Needed	Proposed Solutions
4. Encourage CLIP	CLIP is newly launched and still finding its way.	Support required for ongoing capacity building. Development of key modes of communication with membership base will be important.	9. Online platforms supporting community development for CLIP 10. Regular CLIP meetings
5. Promote financial independence	Helping families generate incomes, access health insurance and supporting children to attend school will all reduce poverty longer term for CLIP members	Encourage children to attend school by providing awards for children Posters with anti-bullying messages for schools / link in with other NCD communities for messaging	11. Sustainable funding solutions explored so work of Community Development Officer can continue

Appendix 2 Multisectoral collaborative action to reduce regional inequities and optimise quality of life for children living with CAH in Pakistan

Situation: Children living with CAH in Australia and other high-income countries enjoy an excellent quality of life, normal life expectancy and are able to live to their full capacity. Children living with CAH in Pakistan and other low income countries experience inequitable preventable morbidity, mortality, disability and social stigma.

Ultimate goal: Equitable quality of life for children living with CAH in high and low income countries internationally.



Appendix 3 Budget for CLIP Project

Action	Proposed	Actual	Details	Total
Translation of CAH PepTalk and injection kit handouts into Urdu <ul style="list-style-type: none"> online access to dubbed video handouts distributed at CLIP meeting 	\$5,500	\$5,500	Translations completed and Urdu CAH PepTalk due for online launch in early 2018	\$5,500
Printing of Garry Warne booklet on CAH x 1,000 copies	\$2,000	\$2,000	Printed and given free to all CAH families through SPED network	\$2,000
Translation of Hsu & Rivkees book into Urdu and printed x 1,000	\$5,000	\$0	Funds transferred to CAH register and Mobile Phone app	\$0
Support for capacity building to strengthen CLIP community: <ul style="list-style-type: none"> quarterly education sessions for CLIP (link to outpatient department dates) hosted by health care professionals educational support for health professionals (so they can support CLIP) / webinars CAH treatment guidelines available development of ongoing communication channel (for families and health professionals) Strengthen CLIP community: <ul style="list-style-type: none"> quarterly education sessions for CLIP (link to outpatient department dates) hosted by health care professionals educational support for health professionals (so they can support CLIP) / webinars CAH treatment guidelines available development of ongoing communication channel (for families and health professionals) mobile phone app development and launch CAH Rights Flyer development and launch community Development Officer support of ongoing activities of CLIP 	\$6,000	\$13,300	CAH Register development and launch Mobile phone app development and launch CAH Rights Flyer development and launch Community Development Officer support of ongoing activities of CLIP	\$13,300
Support for annual NCD Symposium to connect CLIP with other childhood NCD Communities and engage health professionals in building the capacity of CLIP	\$3,000	\$3,000	Support of NCD Child Symposium Dr Baloch presented at World Public Health Congress Advocacy video	\$3,000
Support to reduce poverty <ul style="list-style-type: none"> school awards posters for NCD Conference 	\$1,500	\$1,500	Launch of CAH Rights Flyer CLIP meetings	\$1,500
TOTAL	\$23,000	\$25,300		\$25,000



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