



Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



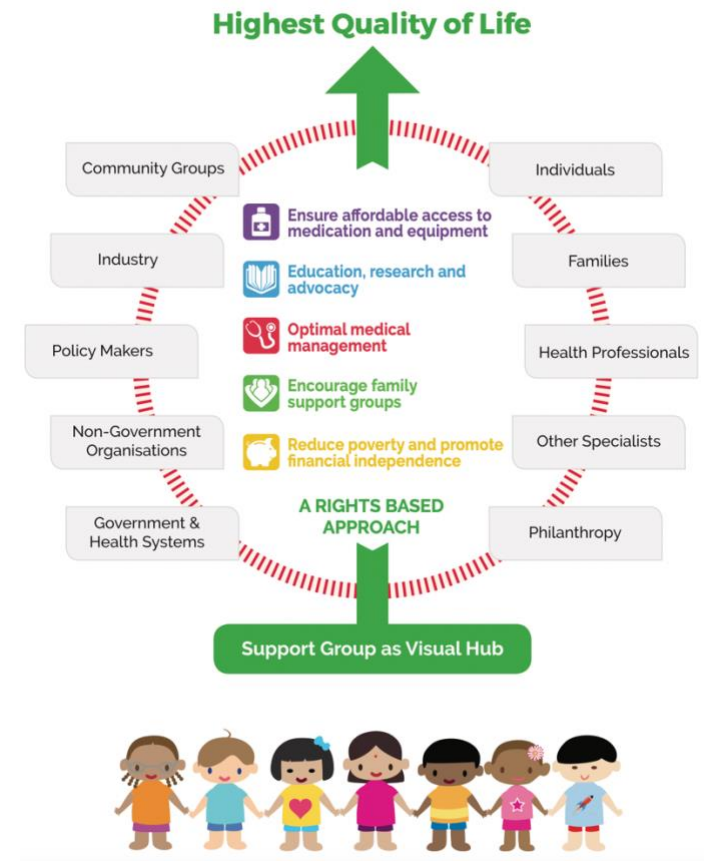
Checklist to assist with planning, delivery and evaluation of Childhood NCD Community Club Meetings

CLAN’s Strategic Framework for Action maintains communities of children living with the same non-communicable disease (NCD) or other chronic health condition as the visual hub of collaborative, multisectoral action that focuses on five pillars:

- 1) Affordable access to essential medicines and equipment
- 2) Education, research and advocacy
- 3) Optimisation of medical management
- 4) Encouragement of family support groups and
- 5) Reducing financial burdens on families.

Supporting NCD Communities to come together in person (or online) for education, encouragement, networking and consultation is core to the implementation of CLAN’s Strategic Framework for Action.

This Club Checklist was last updated in **August 2023**. Please notify CLAN of any additional tips you have found useful running your Club meeting, and we will add it to this list to help others prepare future meetings.





Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



Pillar	To Do CHECK LIST to prepare for CLAN Club Meetings for Chronic Health Condition XYZ	Measure of success	Person Responsible
<p>Pillar 1 - Access to essential medicines and equipment</p>	<p>Consult with community members to determine whether affordable access to medicine or equipment is a major challenge. This is essential; if families are not able to affordably access the medicines and equipment they need to optimally care for their children, then EVERY question at the Club meeting will focus on access to medicines / equipment. It is very important to do as much as possible in advance to secure affordable access to essential medicines and equipment for all families so they can focus on educational materials and opportunities at Club meetings.</p> <p>CLAN has found it most effective to work with the community, health professionals and other key stakeholders to put in place short, medium and long-term solutions:</p> <p>a) <u>Short-term solutions</u> - if affordable access to medicines or equipment is a challenge for families, consider organising humanitarian donation beforehand so they can be given out at Club meeting (eg CLAN used to give free Hysone and Florinef at start of CAH work, before drugs were registered in-country; arranged donation of urine dipsticks for NS Club</p>	<p>Should be: S - specific M - measurable A - achievable R - relevant T – time bound</p>	



www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



	<p>and BGL testing strips for Diabetes; bisphosphonates were sent to Fiji prior to OI Wishbone Day celebrations). Aim to provide a continuous, uninterrupted supply for at least 3 years. Discuss distribution plans for day (and beyond) with hospital staff; distribute through hospital pharmacy where possible. Include any associated costs in Club meeting budget. Use CLAN CHECC Scorecard to determine which children should received donated goods free if there is not enough for all.</p> <p><u>b) Medium-term solutions</u> – consider sustainability options. Where possible, work towards registration of drugs in-country to ensure longer-term access and inclusion on NEML (National Essential Medicines List)</p> <p><u>c) Long-term solutions</u> - consider options to improve affordability (eg inclusion of drugs on national health insurance list; Universal Health Coverage; innovative income generation for families; children attending school)</p> <p>Ensure Newborn Screening for CAH is universally available (at minimum, a pilot to establish true incidence of CAH is essential to estimate mortality).</p> <p>Consult the @MATES4Kids Toolkit (available on the WHO Knowledge Action Portal) for more information on how to improve access.</p>	
--	--	--



Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



Pillar 2 - Education Research & Advocacy	<p><u>a) Education</u></p> <ul style="list-style-type: none"> • Consider educational needs of ALL stakeholders, including children, families, health professionals, policy makers, national and international community. • Translate the “bible” on condition XYZ into local language and arrange printing and distribution so booklets can be given free to all families at the Club meeting. This booklet supports education of health professionals, the media and politicians alike • All presentations from visiting speakers to be translated into local language; printed copies of powerpoint slides to be given to families on the day (they will forget most of what they hear otherwise) • After Club meeting ensure translated educational resources also available online for families (eg pdf) with brief report (including group photos) of meeting • Newsletter provided for all families at the Club meeting. Should include articles and information about the particular condition; letters of encouragement from other international community groups; encouraging stories about individuals living fulfilling lives with the condition; FAQs; key messages from the hospital etc 		
---	--	--	--



www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



	<ul style="list-style-type: none"> • In the absence of quality information all communities develop myths to fill the void. Identify key myths held by the community in advance (eg hydrocortisone given for CAH weakens the bones so children shouldn't play games) and plan content / resources to dispel myths <p><u>b) Research</u></p> <ul style="list-style-type: none"> • Use patient registers to establish mortality rates, incidence, prevalence, health outcomes, PREMs, PROMs etc • Take opportunity to consult with the families at the Club meeting to conduct a community health needs assessment (HNA). CLAN has proforma available that can easily be locally adapted for each Club. This information should guide advocacy efforts and planning prior to next annual Club meeting. Seeks ethics approval in advance if you plan to publish the results. • Consider publishing results of survey in journal (arrange Ethics in advance if you plan to do this) • Ensure formal evaluation conducted at end of Club meeting to help improve future meetings (CLAN has proforma) 	
--	---	--



www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



c) Advocacy

- Invite media to the Club meeting (help raise awareness)
- Distribute CLAN Child-Friendly Rights Flyers to all children and families, and ensure everyone is aware of the UN Convention on the Rights of the Child
- Use social media platform for connecting nationally & internationally
- Consider setting up fundraising page online and promote to international community (helps connect others)
- Consider inviting politicians / MOH if access to medicine an issue
- If international guests attending, consider inviting Embassy officials from their country to participate
- Consider developing a video of the Club meeting. This will require advance planning (videographer, permission of hospitals and families etc) but can be very worthwhile – Club videos are effective tools to support future fundraising, advocacy and awareness efforts.
- Identify and leverage international awareness days wherever possible.
- Develop hashtags for use to raise awareness.



Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



<p>Pillar 3 -</p> <p>Optimal Medical Management</p>	<p>Consider a range of options to optimise medical management:</p> <p><u>a) Guidelines</u></p> <ul style="list-style-type: none"> • Consider translation of treatment guidelines / protocols into local language to streamline future management at hospital. Disseminate nationally. Let families know the guidelines exist (so they know standard of care to expect when they attend a health facility) • Ensure guidelines and Club activities encompass holistic approach to prevention, management (bio-psycho-social with focus on prevention) and transition of adolescents to adult services. • Establish systems to support newly diagnosed children / families <p><u>b) Professional development and capacity building</u></p> <ul style="list-style-type: none"> • Promote multidisciplinary approach to health care; engage range of health professionals in Club planning, implementation and evaluation • Run educational training sessions for local health professionals by national specialists / visiting experts the day BEFORE the Club meeting (in this way all health professionals answer families' questions the same, and there is no loss of face). 		
---	--	--	--

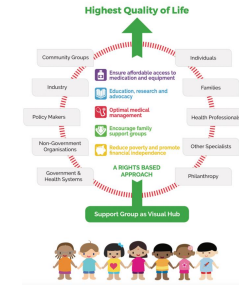


www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



	<ul style="list-style-type: none"> • Consider acknowledgement certificates for participants in training sessions to support CPD (Continuing Professional Development). • Establish a national professional society (eg Paediatric Endocrinology Society) to promote consistently high standards of care • Encourage health professionals to engage in international conferences <p><u>c) Health system strengthening</u></p> <ul style="list-style-type: none"> • Explore development of a patient register (local and national) to support ongoing care and monitoring of health outcomes, as well as strengthening local, national and international research • Presentations at Club to help families understand best processes to follow for OPD care / routine review / care during emergencies etc • Invite officials from Ministry of Health and Education to attend 	
--	---	--



Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



Pillar 4 - Encourage Support Group	<p><u>a) Club structure</u></p> <ul style="list-style-type: none"> • Ensure there is sufficient time set aside in the Club meeting to vote for the Club executive / to hold elections / introduce leaders / exchange mobile phone numbers / speak about problems etc. The Club Executive should be involved (take leading role) in planning future Club meetings. Note – this is hard if condition is a disease of poverty (eg RHD); community will require support for much longer in this instance • Help Club execs learn how to fundraise and connect internationally for support (build sustainability and independence) <p><u>b) Strengthen partnerships</u></p> <ul style="list-style-type: none"> • As per CLAN’s strategic framework, consider which partners / stakeholders should be engaged and invited to attend the Club; this will depend on community process and cultural factors. Who are leading organisations locally, nationally and internationally? • Identify leading international support groups in HICs; update them on upcoming Club meeting; invite them to be involved, 		
---	---	--	--



www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



	<p>present at Club / health professional meetings, support activities, or at a minimum, share letter of encouragement</p> <ul style="list-style-type: none"> • Identify sponsorship opportunities (local, national, international) <p><u>c) Build community</u></p> <ul style="list-style-type: none"> • Take photos and possible video footage at the Club meetings to promote Clubs in future • Identify and establish platforms to best support community (eg Facebook page / Watts App / Twitter / web-site, mobile apps) • Ensure fun activities are available for children on the day • Use lunch break to promote socializing between families • Share report of meeting with international partners / online / help with awareness • Work with Club Executive to determine name of Club (eg should NOT be called the “CLAN Club” – should have a name that families identify with and feel sense of belonging to). Examples of names other communities have come up with include: CAHSAPI (CAH, Philippines); IKAHAK and KAHAKI (Indonesia); CLIP (CAH, Pakistan) etc. Also work with Club over time to develop a logo, communication platform (eg Whats App or Facebook) and website 	
--	--	--



www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



<p>Pillar 5 -</p> <p>Reduce Financial Burdens</p>	<p>a) <u>Reduce financial burdens</u></p> <ul style="list-style-type: none"> • Integrate questions within community survey to help identify key burdens and costs to families and ways to reduce financial burdens • Promote health insurance • Identify all government-led financial support mechanisms available to families and ensure families are provided with culturally safe information (eg simple written / infographic summary in local language) outlining how to access same. Establish systems to ensure all families of children who are newly diagnosed receive this information also. <p>b) <u>Identify children living in most vulnerable circumstances</u></p> <ul style="list-style-type: none"> • Use CLAN CHECC Scorecard to identify children living in the most vulnerable circumstances and prioritise action and support to increase the chances these children with survive and thrive. (More information available here) <p>c) <u>Consider different types of meeting</u></p> <ul style="list-style-type: none"> • Consult with community to establish preferences for meeting (eg face to face, online, hybrid). Hybrid format may allow those living far away 		
---	--	--	--



www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



to attend, but also cater to those without internet access.

c) Promote financial independence

- Provide information to families on full range of financial support options available (eg government support; health insurance; local NGOs; ethical and established enterprise development schemes etc)
- Consider income generation activities community could engage in. CLAN has examples of this that we can share. However, essential to note any financial innovations can be potentially risky, so must be done very carefully. Ensure “above all do no harm”; separate doctors from financials dealings so families don’t lose face with their health care providers (could result in “loss to follow up”).

d) Schooling and education

- Monitor percentage of school-aged children attending school as marker of success; track change over time
- Ensure recognition of importance of schooling is built into the meeting. Acknowledge students doing well at school; find sponsors to support gifts for children doing well at school.



Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



<p>Pillar 6 – Ethical Project Management / General Admin</p>	<p><u>a) Planning -</u></p> <ul style="list-style-type: none"> • Complete “CLAN Plan for (condition XYZ)” in consultation with key stakeholders and partners, to ensure clear strategic plan • Maintain community development focus at all times (rights-based) • Codesign event with Community leaders wherever possible (noting many childhood NCD Community members are initially very impoverished with very little capacity for engagement. Although they may have limited ability to support planning, implementation and evaluation in early stages it is essential to continue to make every effort to engage and consult with them throughout – ultimately they will take over leadership role) • Engagement and involvement of a broad range of multisectoral partners bodes well for longer term change and sustainability. The less partners and sectors involved, the less likely sustainable change will be. • Families and children must remain the visual hub of all action • Involve interested stakeholders in codesign and planning where appropriate (share CLAN’s strategic framework for action with potential partners to communicate overall goal) 		
---	--	--	--

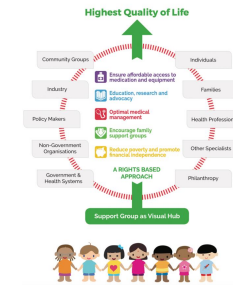


www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



	<ul style="list-style-type: none"> • Use project management tools to support planning where possible (CLAN can support with program logic, work plans, budget, Club checklist, evaluation templates etc). • Share date for Club meeting with CLAN and other partners as far in advance as possible (to maximise opportunity for collaboration with / messaging from any international groups) • Determine key goals for Club meeting (based on community priority) and develop evaluation strategy (and identify indicators) at start of planning • Contact families through hospital if the Club is new and through the club executive if an established club • Where possible, hold Club meetings at hospital (this is a natural geographic hub that all families naturally gravitate towards / reduced financial burden on families) • Develop budget for event. Budget must protect families from financial burden associated with attending Club meeting. CLAN budgets on amount per family (budget to cover cost of meals / snacks for families, loss of income, cost of travel – families should not be out of pocket) • Consider topics families will want to know about and speakers they would learn most from. Invite speakers well in advance. • Consider specific topics of importance (eg adolescence; transitional care) • Develop a social media strategy – engage partners; consider hashtags 	
--	---	--



www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



	<ul style="list-style-type: none"> • Develop longer term fundraising strategy / partnership management plan / communication strategy / risk management strategy • Ensure those planning Club activities and Club Executive members are aware that the CLAN Online Policy Handbook (including our Complaints Policy) are online at www.clanchildhealth.org in the Contact Us section. Club Executive are asked to communicate to Club members that this information is available and where it is available. To this end, CLAN would ask that our web address be widely disseminated at Club meetings and in any newsletters or communications to families. CLAN will support networking of Club with other international organisations. <p><u>b) Implementation</u></p> <ul style="list-style-type: none"> • Develop and follow agenda for meeting. Agenda should include timeline, speakers, topics, Q&A sessions, surveys of families; lunch / snack breaks • Arrange fun activities and volunteers to help entertain the children whilst parents concentrate on lectures (in the future, children should recall Club Meetings as happy days). CLAN can share previous examples <p><u>c) Evaluation and reporting</u></p> <ul style="list-style-type: none"> • Give evaluation survey to families and key people involved to learn how to improve future meetings 	
--	--	--



www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



- Report on Club to be prepared and disseminated to broad range of stakeholders after the meeting (include photos, number of attendees, activities undertaken, media reports, evaluation outcomes etc)
- Ask families at start of day if they give permission for any photos to be used in reports. Explain purpose of photos and reports (to raise awareness; assist with advocacy and fundraising). Invite any families who do not want photos take to indicate to staff member and ensure they are not included in any photos

d) Child and Family wellbeing

- Consider child protection issues; ensure all children are safe and protected during the day; take precautions to ensure no children are at risk during the day in any way
- Consider psychological aspects of event and steps that can be taken to protect and support families (eg sensitivities around discussions on ambiguous genitalia in CAH meetings should be considered deeply in advance and managed professionally and empathetically; children should never be made to feel embarrassed or ashamed; consider having psychological support at meetings in case families become upset)