



CLAN is dedicated to 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 and happy lives and know their neighbours care.

## **PROJECT REPORT: NODDING SYNDROME SUPPORT GROUPS LAUNCH HELD ON 12<sup>TH</sup> MAY 2018 AT HOPE FOR HUMANS CENTRE, ODEK SUBCOUNTY, OMORO DISTRICT UGANDA**

### **Introduction:**

Nodding disease is a chronic debilitating disease that weakens muscles and makes head loll on the shoulders, it is also characterized with seizures. It has over the years affected a big proportion in Northern Uganda. In 2012, there was an estimated effect of more than 3000 victims of nodding disease, a few years later, studies indicate a gross impact to more than 8000 children commonly between the ages of 5-15 years and expanding from initial 3 districts (Pader, Kitgum and Lamwo) to also Gulu, Amuru, Oyam, Lira and Omoro districts.

With support from Caring and Living As Neighbors ([www.clanchildhealth.org](http://www.clanchildhealth.org)) and collaboration with Fabs Organization, a Ugandan based community organization that deals in advocacy for women and children's rights, we carried out a 2 day project that saw us conduct a training for health workers and later launching the Nodding syndrome support group on day 2.

### **DAY 1 ACTIVITIES**

Day 1 was basically to train health workers about Nodding syndrome and advocacy in the Nodding syndrome, as well as explain and elaborate more about the project objectives and goals.

The training involved 35 participants including medical students, doctors, clinical officers, psychiatric nurses and community health workers, most of whom have been participating in the management of Nodding syndrome affected children.

In a full day capacity building training by Pediatrician, participants were able to learn about Nodding Syndrome, the existing gaps in research, current management and next steps. Participants were also able to suggest what can be done in the field based on their ground experience.

Dr. Twineamatsiko Andrew, youth advocate CLAN discussed the project content with the team including the short term, medium, and long term. These were based on the 5 pillars; access to medicines, education, research and advocacy, optimal medical management, encouraging nodding syndrome support groups and reducing poverty and building financial independence.

Participants were asked to have suggestions on the project goals and outcomes and what they thought could be changed or done.



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The participants then had a training on advocacy and usage of the communities as advocacy champions for the Nodding syndrome challenges.

### **Outcomes;**

1. Successfully trained 35 health workers
2. VHTs were empowered to drive project through communities
3. Medical students established a technical working group to be mentored and continue supporting the project
4. A future plan to develop an advocacy agenda that both health workers and families will use
5. A post training evaluation conducted

### **Challenges**

1. Limited resources to support more participants,
2. Limited logistics
3. Limited time for the training content
4. Varying levels of education

### **DAY 2 ACTIVITIES**

Day 2 was a day to launch the Nodding syndrome support groups, the launch was held at Hope for Humans centre in Odek, Omoro district, this was a centre that used to support Nodding syndrome children before closure.

In attendance were supporting organisations; Fabs Organisation, District health leadership, SAGE an organization that supports agriculture, media and the local community both affected by Nodding syndrome and those not.

Several activities held included; visiting affected children, training for the families affected by Nodding syndrome about the project, education for the whole community on Nodding syndrome and project, SAGE training on communal commercial agriculture, launch of support group.

Day started with Dr. Twineamatsiko Andrew introducing the entire team after local council leaders welcome remarks, introduction included a brief about Nodding Syndrome and project but as well about the training conducted a day before.



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The community health worker together with the District Nodding Syndrome coordinator then explained to families the core objectives of the project, including the goals for the project, described the CLAN 5 pillar model and what it plans to achieve, encouraged communities to be proactive and promised to keep supporting and monitoring their Group meetings.

SAGE our first project partners the conducted a training on commercial communal agriculture, usage of available land to grow crops for sale, role of combining land to maximize harvests and role of mechanization. SAGE promised to provide free seeds for the support groups, do free ploughing for their land and later support harvesting of the final product, it will then provide market/purchase the final products. This will be after a memorandum of Understanding with the Nodding syndrome support group once they plan to opt for agriculture, this project will be supervised by our project team member, SAGE representative and the community development officer.

After the trainings, there were speeches by the district health officials, and the leader of the recently created Nodding syndrome support group thanking the team for the initiative and CLAN for support.

The group was officially launched by District Nodding syndrome coordinator and given mandate to fully operationalize and encouraged group to stick together.

### **Outcomes**

1. Established the 1<sup>st</sup> family support group comprising of 16 members.
2. Elected leadership of the Nodding syndrome family support group.
3. The formed group decided to be meeting weekly and also formed a financial savings group for every member to save weekly.
4. We supported financially the capital into their savings group.
5. SAGE will support commercial agriculture for the group.
6. Communities not affected by Nodding syndrome also requested to form groups and benefit from the commercial agriculture.
7. Empowered community health workers and community development officer to guide and support the family support group.
8. The support group to engage their children in advocacy activities for their rights but as well ensure they also take part in the various rehabilitation activities.
9. District to support growth of the project after submission of the report.
10. An advocacy speech by support group leader
11. Commitment by the local communities to see project to a success.



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## Challenges

1. The event was attended by more than 200 people both affected by Nodding Syndrome and those not affected, costly in terms of logistics
2. Other Non-affected nodding syndrome families established their groups for agriculture which unfortunately won't be supported and guided by our team because of numbers and capacity.
3. Children in the Support group formed had mental retardation and were not able to take part in the art contest we had planned.
4. Initially invited guests were not able to make it because of the President's visit in the region. Late cancellations affected our planning.
5. Community mistrust in their top leadership.

This report on behalf of the team has been prepared by;

Dr. Twineamatsiko Andrew

Project team leader

**\*PICTORIALS ATTACHED SEPARATELY\***