

# 7<sup>th</sup> Global Patients Congress

9-11 April 2016



International Alliance of  
Patients' Organizations  
A global voice for patients

Selsdon Park Hotel, South London, UK • [www.globalpatientscongress.org](http://www.globalpatientscongress.org) #GPC2016

**Innovation in rare or stigmatized diseases and disorders and treatment**

**Joshua Wamboga**

Executive Director, Uganda Network of AIDS Service Organizations (UNASO)

## **Nodding disease: a devastating condition in northern Uganda**

- A rare and unexplained brain disease affected more than 3,000 children in northern Uganda and south Sudan ( area recovering from two decades of civil war) .
- It is a mentally and physically disabling disease that only affects children, typically between the ages of 5 and 15. Nodding disease is found exclusively among the children of refugee families
- Communities in panic and some people are losing hope as the medical community struggles to either find a cause or a cure.
- Neighbors don't allow their children to interact with those affected. affected families are isolated.

## Patients groups and Parents Do The Best They Can

- Patient groups and care givers have advanced to researchers hypothesis of the most likely cause of the disease based on the observation that children present with.
- Theories by patients groups to researchers; an infective agent transmitted by the blackly, consumption of fungal-infected food products with toxic chemical weapons during the upsurge of the civil conflict in the mid-1990s;It could be an effect of the war. There were many deaths around this area - many people were killed. So maybe it is their spirit which is making these children sick.
- An inter-disciplinary group of researchers asked the patients groups and local population what they thought were the causes of the disease. One explanation was that people who died in the war and were not buried in the traditional way brought misfortune to the community.

## Patients innovation cont.

- More interesting for the scientists was the suggestion by patients that food aid distributed by the World Food Program (WFP) was the cause
- Patient groups developed Local herbs and ritual as anti-convulsant treatment
- Patient groups worked with clinical outreach teams to make house visits every month to see the children.
- The Epilepsy Support Association Uganda introduced a drama intervention in which communities would be entertained with a play while getting the right information on epilepsy.
- Individuals would be encouraged to participate in the drama or explain to the audience what they would have learnt. The use of “forum theatre” helped to demystify epilepsy and nodding syndrome.
- Patient groups championing the removal of children from their homes if they think the child is neglected.

## The importance of patients disease knowledge

- For the researchers, patients theories were promising new avenues to explore.
- Researchers have come up with an alternative; Generous helpings of milk and food supplements produced a swift improvement in the children's condition which then stabilized.
- Government assisted by WHO and other partners set up treatment centres where affected children got treatment and were also given food supplements.
- The Epilepsy Support Association Uganda (ESAU) and other patient support groups intensified community sensitization through forum theatre to reduce the false beliefs and social stigma attached to the disease. Many patients were now seeking medical treatment and recovering from the seizures
- Based on this initial success, the researchers are hopeful that they can now find an effective cure.
- New anti-epileptic drugs were introduced (sodium valproate) and have been effective in treating nodding disease.

## The importance of patients local knowledge

- Fresh information has now come from a new study carried out by the University of Gulu in northern Uganda. It sees a link between the illness and the consequences of the civil war in the region.
- A study by Gulu university has linked nodding syndrome to a combination of epilepsy and malnutrition
- They are enthusiastic about working with patients groups & local communities and organizations to find the true cause of NS and to understand the epidemiology of this disease in terms of incidence, prevalence and progression.
- The study will create a platform for treatment intervention studies and will inform authorities on how to improve the disease management and prevention strategies.

# 'takeaways'

- Patients advancing the possible theories of diseases outbreak to researchers
- Patient groups mobilizing community and working with fact-finding mission(Gulu University) to start a research programme focused on the etiology of this disease.

The innovations by ESAU and other patient groups to create awareness on NS through forum theatre led to double increase in the number of patients visiting health facilities for treatment. Patients were encouraged to form small support groups through which they could be served by government programmes to enhance their incomes and livelihoods.

Unfortunately the drama sessions could not continue as funding for this activity run out mid last year. The groups that were formed are continuing to mobilize new patients at a small scale

- Faced with a rising caseload, patient groups called on the Ugandan government to address nodding disease in the Acholi sub-region by investing US\$2.9 million plan calls for sensitization programmes aimed at making parents take their children to health centers for check-ups
- Many children that had dropped out of school due to NS have now returned as the seizures reduced while others are being taken care of by their families who have better information on NS and are now able to treat it medically.

# Contact us: Epilepsy Support Association Uganda (ESAU),

Uganda Alliance of patients organizations (UAPO) and its members

1. Epilepsy Support Association Uganda (ESAU) :[www.epilepsy.org.ug](http://www.epilepsy.org.ug) facebook.com / epilepsy .Uganda
2. Community health information and network(CHAIN)
3. The AIDS support Organization (TASO)
4. Sickle cell Association of Uganda(SAU)
5. National care centre(NACARE)
6. Uganda Women cancer organization(UWOSO)
7. National Organization of people living with Hepatitis –B (NOLPH)
8. Joyce fertility support Organization-Uganda (JOYCE)
9. Action group for health and AIDS(AGHA)
10. Uganda diabetes association
11. Uganda Network of AIDS service organizations(UNASO)
12. Uganda National health consumers organization(UNHCO)



# 7<sup>th</sup> Global Patients Congress

9-11 April 2016



International Alliance of  
Patients' Organizations

A global voice for patients

Selsdon Park Hotel, South London, UK • [www.globalpatientscongress.org](http://www.globalpatientscongress.org) #GPC2016

**Thank you**