

NODDING SYNDROME ALLIANCE

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Context

Since the late 90s a plethora of actors¹ including communities, non-governmental organisations, governmental entities, universities and research bodies have striven to achieve a better understanding of the Nodding Syndrome in South Sudan and in the African continent at large. Despite all their individual efforts, fundamental questions concerning the aetiology, the pathogenesis and the epidemiology of Nodding Syndrome remain largely unanswered.

Parallely and on the basis of the available evidence, South Sudan is likely to be the country recording the highest incidence rates of Nodding Syndrome in Africa.

Several factors might have contributed to the current situation:

- a. The difficulty in accessing epidemiological epicentres of the syndrome, ascribable to the prolonged insecurity due to ongoing conflicts in the country;*
- b. The prevailing humanitarian imperative which is constantly shaping major donors' agenda, with a consequential focus on communicable diseases and emergency response rather than on chronic and less life-threatening conditions;*
- c. The constrained resources, capacity and coordination existing within the country to address the multiple needs of communities affected by the syndrome;*
- d. The uncertainty deriving from the above-listed unanswered questions, which in turn undermines the definition of an effective clinical approach to and treatment of the syndrome.*

The “International Scientific Meeting on Nodding Syndrome” held in Kampala in 2012 defined Nodding Syndrome as a form of epilepsy, with the latter being the most common chronic brain disease in the world. Furthermore, in recent years scientific findings have indicated a significant correlation between Nodding Syndrome and Onchocerciasis (i.e. one of the main Neglected Tropical Diseases), leading some researchers to hypothesise a casual association between the two and to consider the former a co-morbidity of the latter².

¹ Such as the Ministry of Health of the Republic of South Sudan, the University of Antwerp, the University of Amsterdam, Amref Health Africa, Light for the World, Sudan Evangelical Mission, CUAMM, OVCI.

² N Gumisiriza, F Mubiru, JN Siewe Fodjo, M Mbonye Kayitale, A Hotterbeekx, R Idro, I Makumbi, T Lakwo, B Opar, J Kaducu, JF Wamala & R Colebunders, “Prevalence and incidence of nodding syndrome and other forms of epilepsy in onchocerciasis-endemic areas in northern Uganda after the implementation of onchocerciasis control measures”, in *Infectious Diseases of Poverty*, 9 : 12 (2020).

These classifications have positioned the Nodding Syndrome within the realms of non-communicable diseases, disability as well as neglected tropical diseases, thus widening the range of actors with relevant sectoral expertise which are interested in understanding and tackling the condition. Moreover, the psychosocial impact of Nodding Syndrome at individual, familial and community level is being increasingly appreciated: this calls for an even broader collaboration, in order to adequately address the consequences of the syndrome in terms of education, livelihood and social integration.

Why the Alliance

Over the last three decades the institutional agenda in South Sudan has been primarily informed by humanitarian needs³. Amref Health Africa acknowledges and supports the humanitarian imperative; however, in the longer term, Amref Health Africa does also acknowledge the critical challenge emerging from side-lining non-communicable conditions such as the Nodding Syndrome and their impact on communities.

Amref Health Africa believes that this condition deserves a greater effort by all stakeholders – and an alliance would provide an ideal vector to harmonize and govern this joint effort.

An alliance, conceived as a network of committed parties that emanates from the closed setup of the current grant-specific consortium, would better address and bridge many of the hindrances and gaps that have so far undermined a more effective response to the issue of the Nodding Syndrome in South Sudan. For instance, by recalling all the previously mentioned challenges, it would:



Promote collaboration among several stakeholders and synergies across their individual and/or joint interventions;



Encourage wider sharing of knowledge and best practices, to build a more robust evidence base to respond to key questions on aetiology, pathogenesis, epidemiology and treatment of Nodding Syndrome;



Improve access, thanks to the different operational presence of multiple actors, despite the existing insecurity in the country;



Provide a larger and thus more relevant advocacy platform, holding more leverage when negotiating for political and strategic consideration towards the Nodding Syndrome epidemic vis-à-vis the pressing humanitarian needs of the country;



Help harmonize communication and dissemination of information concerning the Nodding Syndrome across stakeholders, with clear advantages in terms of advocacy effectiveness;

³ See, for instance, the South Sudan Humanitarian Response Plan 2020 available at the following link: <https://reliefweb.int/report/south-sudan/south-sudan-humanitarian-response-plan-2020-december-2020>



Facilitate the conduction of joint efforts to raise and pool more resources for the cause, from more sources, at the same time increasing efficiency and reducing even further the risk of duplication and overlapping of interventions;



Offer a synergetic technical and operational forum for organizations which vary greatly in nature, sectoral expertise and capacity – but which are, nevertheless, committed to holistically address the condition and its various consequences;



Provide a longer-term perspective and commitment on the issue, to ensure programmatic continuity: the Nodding Syndrome is a chronic condition, which requires continuous support well beyond the time-constrained cycles of single grants;



Increase the chances of seizing opportunities to integrate responses to the Nodding Syndrome with interventions pertaining NTDs, disability, non-communicable diseases and mental health.

Tentative goals

Overall goal:

Contribute to the wellbeing of human beings affected by Nodding Syndrome, their families and their communities

Specific goals 2020 - 2024:

- 1. To become a recognized topic-specific knowledge and advocacy platform, offering mid-to-long term technical and strategic guidance on Nodding Syndrome to its members as well as to the global community;*
- 2. To promote donor education initiatives aiming at securing long-term financial and programmatic sustainability of Nodding Syndrome interventions in South Sudan;*
- 3. To facilitate the identification of suitable funding opportunities and promotion of relevant consortia within the alliance.*

Tentative governance and membership rules

Amref Health Africa envisages the establishment of a Secretariat at the helm of the “Nodding Syndrome Alliance”. The Secretariat comprises of Organisations elected by the Nodding Syndrome Alliance every 3 years.

The Secretariat drafts and proposes Terms of References to define how the alliance works; there are evaluated and approved by the members. The Secretariat, in consultation with members, drafts and proposes strategic and work plans for the alliance, with specific and agreed-upon deliverables and targets.

The Secretariat calls for bi-yearly meetings with the Plenary and guides internal consultations.

The Secretariat coordinates the work of Technical Working Groups (if any) and provides overall coherency to their outputs.

The Secretariat carries out advocacy on behalf of the entire alliance, targeting relevant stakeholders and the donor community, either directly or through members.

For the time being, Amref Health Africa proposes a free membership scheme until the Nodding Syndrome Alliance reaches 8 members and/or until August 2022. Past one of the two conditions, Amref Health Africa suggests membership should require the payment of a fee of 150 €/year for membership (organisations and governments) and 20 €/year for individual experts (observer status). The funds will be used by the elected lead organisation to cover administrative costs related to the alliance. Acceptance of new memberships is carried out by vote expressed by the members.

How the Nodding Syndrome Alliance may look like

