

# Nodding Syndrome Alliance

## Preliminary data on clinical management from a multi-sectorial initiative addressing nodding syndrome and other forms of epilepsy in Western Equatoria, South Sudan

Authors: C. Scanagatta 1, J.M. Rovarini 2, S.R. Jada 2, F. Tognon 1, P. Franceschi 3, T. Mungumwa 4, F. Manenti 1, G. Putoto 1

1Doctors with Africa CUAMM, Padova, Italy, 2AMREF Health Africa, Juba, South Sudan, 3Doctors with Africa CUAMM, Lui, South Sudan, 4Doctors with Africa CUAMM, Maridi, South Sudan

### Introduction

Nodding Syndrome (NS) is a degenerative neurological condition and form of epilepsy. The causes of NS are unknown; indeed, the global scientific community has been working to determine its aetiology for the last 15 years or so.

Western Equatoria State is the South Sudan epidemiological epicenter, with high prevalence of both NS and Other Forms of Epilepsy (OFE): 4.4% in **Maridi County**, 3.3% (NS: 2.6%) in **Mundri East** and in **Mundri West County** and 5.1% (NS: 2.2%) in **Mvolo County**.

**According to South Sudan Ministry of Health**, the 54% of Epilepsy cases accessing OPD services in South Sudan are reported by these counties (2020).

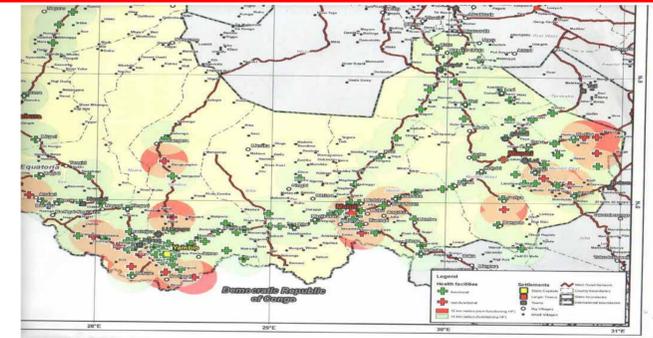
It is estimated that there are at least 10,000 neglected cases of suspected epilepsy/NS in Western Equatoria State.

The “Nodding Syndrome Alliance (NSA)” has been created to answer to such situation, within the framework of a 3-year intervention, funded by the Italian Agency for Development Cooperation and led by Amref Health Africa (AMREF), in collaboration with the NGOs Doctors with Africa CUAMM, OVCI la Nostra Famiglia, Light for the World and Sudan Evangelical Mission (SEM). This consortium aims to provide a pioneering and integrated response to address the needs of communities affected by Nodding Syndrome (NS) and epilepsy in three Counties of Western Equatoria State.

### Setting and Method

The 3-year comprehensive intervention aims at increasing community resilience towards NS/OFE through identification, referral, and treatment as well as socio-economic inclusion of people with NS/OFE. The project funds **3 epilepsy clinics** (Mundri PHCC in Mundri West, Maridi Hospital in Maridi, Lui Hospital in Mundri East), treating NS/OFE and complications.

*By February 2022*, 21 months since inception, the clinics had enrolled and followed up **3357 patients**. Their data have been extracted from the clinics' registers and entered in a dedicated **database** (MS Excel) for comprehensive analysis, a pilot attempt for Ministry of Health being enabled to take informed strategic decisions on this matter.

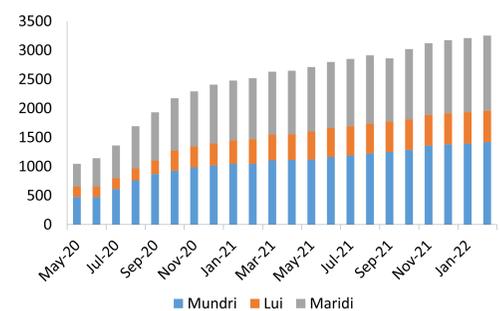


### Results

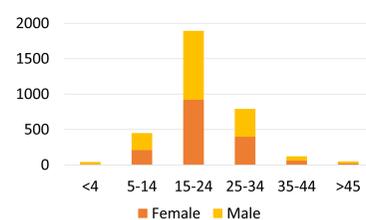
#### Patient's characteristics and diagnosis

	N.	%	
Clinic	Lui	561	16,7
	Maridi	1334	39,7
	Mundri	1462	43,6
Sex	Female	1628	48,5
	Male	1729	51,5
Age group	<4	42	1,3
	5 -14	449	13,4
	15-24	1895	56,4
	25-34	792	23,6
	35-44	122	3,6
	>45	50	1,5
	ND	7	0,2
Diagnosis	Confirmed NS	7	0,2
	Probable NS	570	17,0
	Epilepsy + Probable NS	1535	45,7
	Other Forms of Epilepsy	1243	37,0
	ND	2	0,1
Treatment	Carbamazepine	1811	53,9
	Phenobarbital	788	23,5
	Phenytoin	499	14,9
	Valproic Acid	256	7,6
	ND	3	0,1
Adherence and Outcome	Defaulter (Feb 2022)	1172	34,9
	Dead	24	0,7
	Migrated / Referred to another Epilepsy Clinic	5	0,1

#### Total number of registered patients under care



#### Male / Female distribution



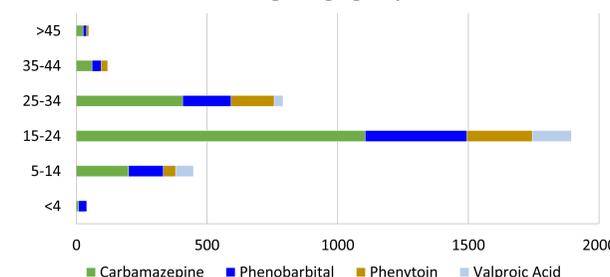
Accurate **diagnosis** remains challenging, with less than 1% of patients under treatment (7) confirmed as NS cases and the relative majority (1535, 45,7%) being reported as having both OEF and Probable NS.

As consequence, **therapeutic choices** are not always fully rational, being also informed by patients preference and being compromised by staff limited knowledge and familiarity with these specific drugs. For instance, VA, the first therapeutic choice for NS is not used with confirmed NS patients

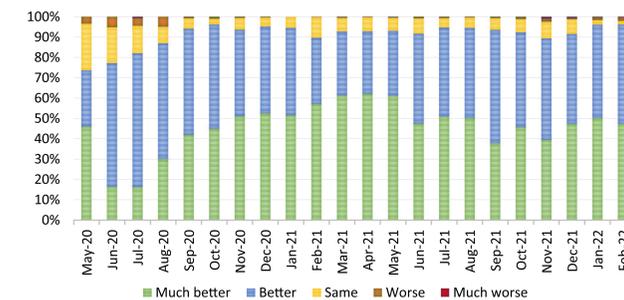
#### Treatment according to diagnosis type

	Confirmed NS	Probable NS	OFE	ND	TOTAL
Carbamazepine	2	969	839	1	1811
Phenobarbital	3	523	262		788
Phenytoin	2	427	70		499
Valproic Acid		184	71	1	256
ND		2	1		3
Total	7	2105	1243	2	3357

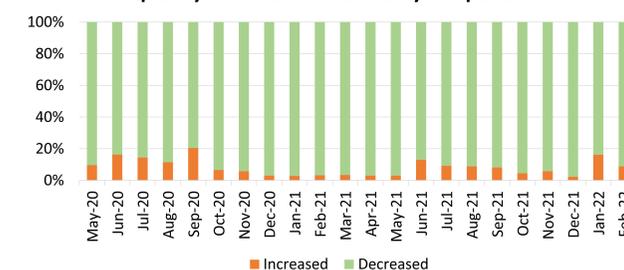
#### Treatment according to age groups



#### Outcome referred by patients every visit



#### Frequency of seizures referred by the patients



The regular administration of drugs is producing good **outcomes on patients** effective and perceived status. Using Feb 2022 as proxy of current situation, the 96% of patients seen at the 3 clinics reported an improvement of their conditions («better» and «much better») and the 91% a drop in the frequency of seizures. In spite of this, other factors (as geographical distance and hard environment, indirect cost of clinic access and fear for stigmatization) are still affecting people compliance with monthly follow up visits schedule; in Feb 2022, the due follow up visit was attended by only 1384 people, the 42% of alive patients.

Given the high number of patients missing their monthly follow up visit, **defaulters** are considered only those missing it for 3 consecutive times. In Feb 2022, the number of defaulters reached 1172 (34,9%). They are mainly men (643, 55%) between 15-24 years old (652, 56%) and diagnosed with OEF and probable NS (631, 54%). Efforts are being done to improve defaulters data reliability and completeness.

#### Defaulters' characteristics and diagnosis

	N.	%	
Clinic	Lui	260	22%
	Maridi	310	26%
	Mundri	602	51%
Sex	Female	529	45%
	Male	643	55%
Age group	<4	19	2%
	5 -14	149	13%
	15-24	652	56%
	25-34	281	24%
	35-44	51	4%
	>45	16	1%
	ND	4	0%
Diagnosis	Confirmed NS	6	1%
	Probable NS	138	12%
Treatment	Epilepsy + Probable NS	631	54%
	Other Forms of Epilepsy	397	34%
	ND	0	0%
	Carbamazepine	522	45%
	Phenobarbital	362	31%
Phenytoin	195	17%	
Valproic Acid	91	8%	
ND	2	0%	

To address the social and cultural factors affecting demand/access/utilization of services for NS and OEF, the project includes **community based initiatives** for suspected cases identification and referral and for patients follow up and support. Although the decision to access services is still depending mainly on family initiative (about 60%), community volunteers are accountable for about the 30% of patients who started the treatment and their follow up (1001). On top of them, community volunteers are following up of the 51% of new patients who had been referred to the clinics because of relatives decision (1061 over 2064). At the moment, community volunteers are therefore following up 2062 people (58% of all reported patients).

### Conclusion

Relevance and feasibility of promoting access to treatment for NS/OFE is confirmed. Further analyzes shall target community networks' contribution to demand for and adherence to treatment, rational use of drugs, patients' provenance and clinical characteristics.