

Global Health Institute of the University of Antwerp presents

# 1<sup>st</sup> International Workshop on Onchocerciasis-Associated Epilepsy (OAE 2017)

12-14 October 2017 | Antwerp | Belgium

Grauwzusters Cloister

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# Welcome

I would like to personally **welcome all of you** to the first International Workshop on Onchocerciasis Associated Epilepsy (OAE). We are very excited to gather researchers, stakeholders and organisations from all around the world here in the next few days.

The aim of this workshop is to **update our knowledge about the different clinical presentations of epilepsy observed in onchocerciasis endemic regions**. It is clear that there is a high prevalence and incidence of epilepsy in many onchocerciasis endemic regions where onchocerciasis is insufficiently controlled. This has been recognised for a long time, but the problem was never addressed in a comprehensive multidisciplinary way. **The burden of disease caused by OAE looks considerable but the exact magnitude still needs to be determined.**

There is **above all a need for action** because the psycho-social and economic consequences of epilepsy in these remote areas are considerable. We cannot wait until the exact pathophysiological mechanism of OAE is known to take action.

Therefore, there is an urgent need to:

- Compare research data from different onchocerciasis endemic regions.
- To explore knowledge, attitudes and practices of health care workers spanning different sectors of health care.
- Establish an OAE policy plan; such plan needs to be pilot tested and evaluated.
- Put OAE on the agenda of public health officials, international organisations and on the list of funders.
- Establish partnerships between researchers, WHO, affected communities, advocacy groups, ministries of health, non-governmental organisations, the pharmaceutical industry and funding organisations.

I hope this workshop will lead to the **creation an OAE alliance** that will become a motor to realise the ultimate goal: **prevent children from developing OAE and considerably improve the quality of life of people and families affected by OAE.**

I would therefore like to thank each of you for attending this workshop and bringing your expertise to our gathering. Attending this workshop shows your commitment, and we could not accomplish our goal without your support, knowledge and experience. So thank you in advance to stay engaged and proactive during this workshop. I would also like to thank the sponsors for their support to make this workshop happening and for allowing to bring OAE under the attention of a wide variety of people.

And now: let's start working!



Prof. Dr. Robert (Bob) Colebunders  
P.I. ERC/NSETHIO and ERCPoC/NSstop  
Global Health Institute, University of Antwerp





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# Programme

Thursday 12 October

**8:00 – 8:30**      **Welcome coffee and registration**

8:30 – 8:45      Welcome and objectives of the workshop  
*Robert Colebunders (Global Health Institute, University of Antwerp, Belgium)*

## **Scientific presentations**

**Chairpersons:** Alfred Njamnshi (University of Yaoundé, Cameroon), Annette C. Kuesel (TDR, WHO)

8:45 – 9 :15      Epilepsy epidemiology in Africa  
*Pierre Marie Preux (Institut d'épidémiologie et de neurologie tropicale, Limoges, France)*

9:15 – 9:45      Update OAE research in Uganda  
*Richard Idro (Department of Paediatrics and Child Health, College of Health Sciences, Makerere University, Kampala, Uganda)*

9:45 – 10:15      Update OAE research in the DRC  
*Michel Mandro (Provincial Health division, Ministry of Health, Ituri, DRC)*

10:15 – 10:45      Discussion

**10:45 – 11:00**      **Coffee & tea break**

## **Scientific presentations**

**Chairpersons:** Thomson Lakwo (Vector Control, Ministry of Health, Uganda), Tony Ukety (NTD expert DRC)

11:00 – 11:15      Update OAE research Tanzania  
*Bruno Mmbando (National Institute of Medical research, Tanga, Tanzania)*

11:15 – 11:45      Update OAE research in Cameroon  
*Michel Boussinesq (Institut de Recherche pour le Développement, Montpellier, France)*  
*Alfred Njamnshi (University of Yaoundé, Cameroon)*

11:45 – 12:00      OAE anthropological research  
*Julia Irani & Maya Ronse (Institute of Tropical medicine, Antwerp, Belgium)*

12:00 – 12:15      Onchocerciasis diagnosis – biomarkers  
*Kenneth Pfarr (Institute for Medical Microbiology, University Hospital of Bonn, Germany)*

12:15 – 12:30      Update entomological investigations  
*Adam Hendy (Institute of Tropical Medicine, Antwerp, Belgium)*



- 12:30 – 14:00**     ***Lunch & possibility to see posters***
- 14:00 – 14:15     OAE a neuro-immunological disease?  
*Tory Johnson (Johns Hopkins University, Baltimore, US)*
- 14:15 – 14:30     Nodding syndrome research by CDC  
*James Sejvar (CDC, Atlanta US)*
- 14:30 – 15:00     Oral poster presentation
- 15:00 – 17:30     **WORKING GROUP 1. ONCHOCERCIASIS BURDEN OF DISEASE (INCLUDING OAE), COST OF OAE**  
Chairpersons: Sarah Mollenkopf (University of Washington, Seattle, US), Natalie Vinkeles-Melchers (Erasmus MC, University Medical Center Rotterdam, Netherlands)
- WORKING GROUP 2: HOW TO IMPROVE SURVEILLANCE FOR EPILEPSY IN ONCHOCERCIASIS ENDEMIC REGIONS AND TO IMPROVE TREATMENT/CARE FOR PERSONS WITH OAE?**  
Chairpersons: Richard Idro (Makerere University, Kampala, Uganda), Pierre-Marie Preux (Institut d'épidémiologie et de neurologie tropicale, Université de Limoges, France)
- WORKING GROUP 3: HOW TO STRENGTHEN WEAK ONCHOCERCIASIS ELIMINATION PROGRAMS, AND PREVENT OAE? NEED TO INVESTIGATE IVERMECTIN RESISTANCE?**  
Chairpersons: María-Gloria Basañez (Imperial College, London, UK), Adrian Hopkins (Neglected and Disabling diseases of Poverty Consultant, Gravesend, Kent, UK)
- WORKING GROUP 4: HOW TO DEAL WITH MISCONCEPTIONS, STIGMA, DISCRIMINATION AND GENDER VIOLENCE ASSOCIATED WITH OAE?**  
Chairpersons: Sarah O'Neill (Institute of Tropical Medicine, Antwerp, Belgium), Alfred Njamnshi (Department of Neurology, University of Yaoundé, Cameroon)
- WORKING GROUP 5: HOW TO IDENTIFY RISK FACTORS FOR AND THE PATHOPHYSIOLOGICAL MECHANISM CAUSING OAE?**  
Chairpersons: Tom Nutman (National Institute of Allergy and Infectious Diseases, Bethesda, US), An Hotterbeekx (Global Health Institute)
- WORKING GROUP 6: HOW TO CREATE AN OAE PARTNERSHIP AND INCREASE FUNDING ? A HUMANITARIAN IMPACT BOND PROPOSAL FOR OAE?**  
Chairpersons: Patrick Suykerbuyk (Global Health Institute, University of Antwerp, Belgium)
- 19:30 - ...**     ***Dinner (optional)***

## Friday 13 October

- 8:30 – 9:00 Report about the WHO 1st Meeting of the Onchocerciasis Technical Advisory Subgroup  
*Wilma Stolk (Erasmus MC, University Medical Center Rotterdam, Netherlands)*
- 9:00 – 9:30 Oral poster presentation
- 9:30 – 10:30 Working groups continue (*same as Thursday*)
- 10:30 – 10:45** ***Coffee & tea break***
- 10:45 – 12:30 Working groups continue (*same as Thursday*)
- 12:30 – 14:00** ***Lunch***
- 14:00 – 15:45 Presentations of the conclusions of the working groups
- 15:45 – 16:00** ***Coffee & tea break***
- 16:00 – 17:00 General discussion about the way forward, the creation of an OAE alliance, writing teams for papers for the journal of infectious diseases of poverty and a policy planning team

## Saturday 14 October

- 9:00 – 10:30 Policy Plan: Working groups
- WRITING TEAM JOURNAL OF INFECTIOUS DISEASE OF POVERTY SUPPLEMENT**  
Chairpersons: Robin Ryder (Global Health Institute, University of Antwerp, Belgium), Charles Mackenzie (Senior Technical Adviser for Onchocerciasis and Lymphatic Filariasis Elimination)
- OUTLINE FOR AN OAE POLICY PLAN (TO BE PRESENTED AT ECTMIH 2017 AND ASTMH 2018)**  
Chairpersons: Patrick Suykerbuyk, Joseph Nelson Siewe (Global Health Institute, University of Antwerp, Belgium)
- 10:30 – 10:45** ***Coffee & tea break***
- 10:45 – 12:30 Policy Plan: Working groups continue
- 12:30 – 14:00** ***Lunch***
- 14:00 – 16:00 Presentations of working groups and general discussion including the planning of a follow up workshop
- 16:00 – ...** ***Closing reception OAE 2017***

# Abstracts

## OAE 2017

1. **Improving the care and the treatment outcomes of children and adolescents with nodding syndrome and other epilepsies through training, support supervision, research, and collaborations in Uganda**  
Abbo C, Mwaka AD, Opar BT, Idro R
2. **Clinical presentation of epilepsy in four villages in an onchocerciasis endemic area in Mahenge, Tanzania**  
Mnacho M, Mmbando BP, Makunde WH, Kakorozya A, Matuja W, Greter H, Suykerbuyk P, Colebunders R
3. **Household burdens of and community response to nodding syndrome in northern Uganda**  
Sato Y, Takei Y, Sakai K, Suzuki S, Kato S, Nishi M
4. **Psychosocial and nutritional support for nodding disease patients: efforts toward sustainability by Taso in Odek sub county, Gulu district**  
Nono D, Oroma A, Grace A
5. **Catatonia in Ugandan nodding syndrome and effects of lorazepam treatment.**  
Kakooza-Mwesige A, Dhossche MD, Idro R, Akena D, Nalugya J, Opar BT
6. **Clinical epidemiological aspects of epilepsy at the general hospital Hason Sendwe, Lubumbashi, R.D. Congo.**  
Kiji MJ, Bilonda ME, Katabwa KJ, Ziata LY, Bukasa KB, Okitundu LD, Mukendi KM
7. **Onchocerciasis associated epilepsy and blackflies in the Democratic Republic of the Congo (DRC).**  
Laudisoit A, Tepage F, Mandro M, Levick B, Suykerbuyk P, Nicaise AD, Michel K, Colebunders R
8. **The social and psychological effects of onchocerciasis associated epilepsy on rural people in Nyantonzi, Masindi, Uganda**  
Mugarura
9. **Cumulative doses of ivermectin and seizure control in children and adolescents with nodding syndrome in Uganda**  
Ningwa A, Ogwang R, Marsh K, Idro R
10. **Asymptomatic *Plasmodium falciparum* malaria and seizure control in children and adolescents with nodding syndrome**  
Ogwang R, Odongkara SP, Torach R, Marsh K, Idro R
11. **Implementation of a community engagement program in the pathogenesis and treatment of nodding syndrome study in Uganda**  
Akun PR, Anguzu R, Ogwang R, Oryema JJI, Ningwa A, Idro R

12. **Onchocerciasis-associated epilepsy and adherence to community directed treatment with ivermectine in an onchocerciasis endemic health district of Masimanimba in the Democratic Republic of the Congo**  
Zola T, Mukendi D, Muhindo H, Maketa V, Matangila J, Mitashi P, Lutumba P
13. **Entomological investigation and geographic distribution of *Simulium spp.* blackflies in relation to nodding syndrome in northern Uganda**  
Zoleta C, Grieco J, Ahern L, Achee N, Kayondo J, Echodu R
14. **Onchocerciasis-associated neurodevelopmental deficits: the hit squad**  
Kashama JM, Bora K, Nseka T, Musasa H, Kambaja B, Bumoko M, Kunyu B, Okitundu D, Mwanza JC, Mumba DN, Tshala-Katumbay D
15. **First evidence by a cohort study in cameroon that onchocerciasis does induce epilepsy**  
Chesnais CB, Njamnshi AK, Zoung-Kanyi Bissek AC, Tatah GY, Nana-Djeunga HC, Kamgno J, Colebunders R, Boussinesq M
16. **Epilepsy prevalence and cohort age shift: evidence for the benefit of ivermectin mass drug administration on onchocerciasis-associated epilepsy in the Mbam valley, Cameroon.**  
Boullé C, Njamnshi AK, Dema F, Mengnjo M, Siewe J, Tatah GY, Zoung-Kanyi Bissek AC, Suykerbuyk P, Pion S, Lenou-Nanga C, Nana-Djeunga HC, Kamgno J, Chesnais C, Boussinesq M, Colebunders R
17. **Age shift of persons with epilepsy in Bilomo, Cameroon, following ivermectin mass drug administration for onchocerciasis. July 2017**  
Njamnshi AK, Zoung-Kanyi Bissek AC, Tabah EN, Ngarka L, Chokote E, Nfor LN, Mengnjo M, Siewe J, Dema F, Tatah GY, Boullé C, Suykerbuyk P, Kamgno J, Chesnais C, Boussinesq M, Colebunders R
18. **Outpatient attendances for epilepsy in onchocerciasis endemic and non-endemic districts of Uganda: an analysis of the 2012-2015 national health management information system data.**  
MK Mbonye, K Couderé, N Van der Moeren, A. Hendy, B Opar, T Lakwo, E Mukooyo, R Colebunders
19. **The gendered burden of nodding syndrome in Cameroon, Tanzania and Uganda**  
Irani JN, Ronse M, Rujumba J, Njamnshi A, Mwaka A, Idro R, Ezekiel M, Semali I, Colebunders R, Peeters K, O'Neill S
20. **Ongoing onchocerciasis transmission and high prevalence of epilepsy despite 19 years of mass distribution of ivermectin in the Mbam valley, an onchocerciasis-endemic region in Cameroon**  
Njamnshi AK, Zoung-Kanyi Bissek A-C., Siewe J, Ngarka L, Chokote E, Nfor L, Mengnjo M, Tabah EN, Dema F, Tatah GY, Boullé C, Suykerbuyk P, Kamgno J, Chesnais C, Pion S, Boussinesq M, Colebunders R

**21. Anxiety and depression in people with epilepsy (pwe) living in an onchocerciasis-endemic region in Cameroon.**

Njamnshi AK, Ntone FE, Zoung-Kanyi Bissek AC, Nfor L, Ngarka L, Chokote E, Mengnjo M, Siewe J, Tabah E, Dema F, Njamnshi WY, Tatah G, Colebunders R

**22. Epilepsy-associated neurocognitive disorders (eand) in an onchocerciasis-endemic region in Cameroon**

Njamnshi AK, Ntone FE, Zoung-Kanyi Bissek AC, Chokote E, Nfor L, Ngarka L, Mengnjo M, Siewe J, Tabah E, Dema F, Njamnshi WY, Tatah G, Colebunders R

**23. The international HIV dementia scale (ihds) for cognitive evaluation of epilepsy patients living in an onchocerciasis-endemic region in Cameroon**

Njamnshi AK, Zoung-Kanyi Bissek AC, Ntone FE, Ngarka L, Chokote E, Nfor L, Mengnjo M, Siewe J, Tabah E, Dema F, Njamnshi WY, Tatah G, Colebunders R

**24. Prevalence and annual incidence of nodding syndrome and other forms of epilepsy in onchocerciasis endemic areas of Northern Uganda**

MK Mbonye, BT Opar, N Gumisiriza, T Lawko, I Makumbi, R Idro, H Onen, R Colebunders

## ECTMIH 2017

- 25. Epidemiology of onchocerciasis and epilepsy in Ituri province in the Democratic Republic of the Congo (DRC)**  
Lenaerts E, Mukendi D, Mandro M, Dolo H, Ucima Wonya' Rossi D, Ngave F, Colebunders R, Suykerbuyk P
- 26. Onchocerciasis associated epilepsy in the Ituri province in the Democratic Republic of the Congo: a case-control study**  
Mandro M, Hasan M, Tepage F, Rossy D, Ngave F, Mambandu G, Kashama JM, Laudisoit A, Colebunders R, Suykerbuyk P
- 27. Clinical presentation of epilepsy in four villages in an onchocerciasis endemic area in Mahenge, Tanzania**  
Mnacho M, Mmbando BP, Makunde WH, Kakorozya A, Matuja W, Greter H, Suykerbuyk P, Colebunders R
- 28. Nodding syndrome is preventable**  
Colebunders R, Tepage F, Ensoy-Musoro C, Mandro M, Bonareri Osoro C, Gumisiriza N, Mmbando B, Rotsaert A, Laudisoit A, Suykerbuyk P
- 29. High prevalence of epilepsy and onchocerciasis after 20 years of ivermectin use in four villages of the Mahenge area in Tanzania**  
Mmbando BP, Mnacho M, Makunde M, Kakorozya A, Matuja W, Greter H, Suykerbuyk P, Colebunders R
- 30. Community-based perceptions of ivermectin in the Sanaga basin of Cameroon**  
Ronse M, Irani JN, Njamnshi AK, Siling K, Teh Monteh C, Ekukole S, Tatah P, Verdonck K, Colebunders R, O'Neill S, Peeters Grietes K
- 31. Epilepsy perceptions and experiences of different stakeholders prior to the implementation of an epilepsy treatment programme in an onchocerciasis endemic region in Ituri, Democratic Republic of the Congo (DRC)**  
Dolo H, Ucima Wonya' Rossi D, Mandro NM, Ngave F, Fraeyman J, Suykerbuyk P, Colebunders R
- 32. Knowledge, attitude and perception about onchocerciasis and ivermectin in the onchocerciasis endemic health zone of Rethy in Ituri, Democratic Republic of the Congo (DRC)**  
Dolo H, Ucima Wonya' Rossi D, Mandro NM, Ngave F, Fraeyman J, Suykerbuyk P, Colebunders R
- 33. Nodding syndrome; clinical manifestations, complications and treatment**  
Idro R, Anguzu R, Akun P, Ogwang R, Opar B, Vincent A, Marsh K
- 34. Nodding syndrome: etiology remains unknown**  
Spencer PS, Palmer VS, Schmutzhard E, Winkler AS

## 1. IMPROVING THE CARE AND THE TREATMENT OUTCOMES OF CHILDREN AND ADOLESCENTS WITH NODDING SYNDROME AND OTHER EPILEPSIES THROUGH TRAINING, SUPPORT SUPERVISION, RESEARCH, AND COLLABORATIONS IN UGANDA

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**Background:** In 2012, The Ugandan Government declared an epidemic of Nodding Syndrome (NS) in the Northern districts of Lamwo, Pader and Kitgum. This region also has a very high burden of other forms of epilepsy. Guidelines were developed and treatment centres established. However, the gap between the desired standards of services available and the services rendered to patients is wide.

**Activities:** To narrow this gap, a series of planning meetings with the Ministry of Health (MOH), academicians, clinicians in relevant fields and development partners took place. As NS is far from being a purely a health condition, the MOH set up a multidisciplinary team to develop a training manual which was later used to train health workers in the syndromic management of NS and other epilepsies. Treatment centers were set up in all the NS affected districts, annual support supervision visits conducted. The findings at these visits and the concurrent clinical research on NS were used to advise on and develop interventions and conduct additional trainings for health workers. Research is on-going.

**Lessons learnt:** The following activities went well: planning meetings, developing the training manual, initial setup of the treatment centers and training of health workers. An audit about 12 months later reported great improvements in seizure control, nutritional status, independence, functioning and general well being. However, especially in Pader district, support supervision found poor seizure control in many children, with complications including severe burns. Antiepileptic drug stock-outs and trained healthworkers migrating away from their work stations were some of the reasons reported for the worsening situation. There were very few multi-disciplinary team members in particular physiotherapists, occupational therapists and special needs teachers, to provide for the complex needs of the patients.

**Conclusion and way forward:** Ongoing research, regular quarterly, support supervision, refresher trainings and updates with new research findings are essential in improving outcomes and care of children with complex diseases. Better integrated care is needed across health, education and social sectors.



## 2. CLINICAL PRESENTATION OF EPILEPSY IN FOUR VILLAGES IN AN ONCHOCERCIASIS ENDEMIC AREA IN MAHENGE, TANZANIA

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<sup>4</sup>Global Health Institute, University of Antwerp, Belgium

**Introduction:** The Mahenge mountains in the Ulanga district in Tanzania is an onchocerciasis endemic area whereby the national Onchocerciasis control programme introduced the community directed treatment with ivermectin (CDTI) since 1997. In 1989, in one rural village in the area, in a very high prevalence of epilepsy (3.7%) was reported. Moreover, children with epilepsy and nodding of the head were first described in the area in 1950.

**Aim:** To describe the clinical presentation of epilepsy in villages known to have a high prevalence of epilepsy in the Mahenge area.

**Methods:** In January 2017, in 2 rural and 2 semi-urban villages, a door to door survey was conducted by community health workers using a 5 questions validated screening questionnaire to identify patients with suspected epilepsy. Persons with suspected epilepsy were then examined by a neurologist. A person was considered to have confirmed epilepsy using the International League Against Epilepsy criteria for epilepsy. Epilepsy suspected individuals were tested for antibodies against *Onchocerca volvulus* IgG4 antigen using the Ov16 test (OV16 rapid test, SD Bioline, Inc).

**Results:** Out of 210 epilepsy suspected individuals, 106 (50.5%) were confirmed to be epileptic. The prevalence of epilepsy in the village with the highest prevalence of epilepsy in 1989 was still high (2.7%). Of epileptic patients, 85(80.2%) knew that they were epileptic and their median age of seizure onset was 12 years (Interquartile range 8 -16). 60 (56.6%) of all seizures were generalized tonic-clonic. Other forms of seizures included atonic seizures 13.2%, absences 7.5%, simple partial 1.9% and complex partial seizures 2.8%, secondarily generalized partial seizures 6.6%. A history of head nodding was reported in 23 (21.7%)(5.6% with past history and 16% present). In 27 (25.5%) there was a family history of seizures. One person (male, 19 years old, 34kg body weight and 142cm height) presented with Nakalanga syndrome features.

**Conclusion:** The peak onset of epilepsy between the ages of 3 to 20 years is a characteristic of onchocerciasis association epilepsy. Nodding syndrome, Nakalanga syndrome and other forms of epilepsy were observed in the same villages.

### 3. HOUSEHOLD BURDENS OF AND COMMUNITY RESPONSE TO NODDING SYNDROME IN NORTHERN UGANDA

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<sup>4</sup>Gulu University, Gulu, Uganda

**Introduction:** Nodding syndrome (NS) is a seizure disorder affecting children in parts of East Africa. The most recent epidemic has been observed in the Acwa river basin in northern Uganda. Although the epidemic seemed to have peaked in 2008, and the number of new cases has dramatically decreased since then, the effects of the disease still haunt the patients because of poor access to health facilities, resistance to anticonvulsants, and progressive mental disabilities. As a local response to the problems, a community-based organization (CBO) was established in 2013 by families affected by NS in Lakwela village, Gulu district, located near the Acwa river.

**Aim:** We conducted ethnographic surveys to describe household burdens of and community response to NS in northern Uganda.

**Methods:** We conducted participatory observations and in-depth interviews with families of NS patients for a total of 24 weeks between September 2014 and September 2017. We also observed and recorded the activities of the CBO.

**Results:** The survey across 97 households revealed that epilepsy affected 10.3% of children (35/339). Most patients reported frequent seizures and developed varying degrees of mental retardation. They also experienced difficulties in fully pursuing household duties expected as household members for their age and sex. Families of patients are also affected due to loss of workforce, excessive care burden, and persistent stigma against the NS symptoms. While the CBO has played a leading role in reducing stigma against NS and in mobilizing local resources to improve the living conditions of NS-affected households, it has little impact in reducing the household burden of patient care, given the organization's limited access to resources and knowledge of appropriate care.

**Conclusion:** The burden of family members may be reduced by reinforcing the community response—that is, providing the CBO with essential resources and knowledge of appropriate care.

#### 4. PSYCHOSOCIAL AND NUTRITIONAL SUPPORT FOR NODDING DISEASE PATIENTS: EFFORTS TOWARD SUSTAINABILITY BY TASO IN ODEK SUB COUNTY, GULU DISTRICT

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**Introduction:** New trends such as the baffling current nodding disease syndrome are posing renewed vulnerability threats to afflicted children and households in some parts of Gulu District. Emerging health complications among children in Gulu has seen over 400 children in only Odek Sub County currently affected the inexplicable nodding disease syndrome. (Gulu District OVC strategic plan 2012-2016, page 10-11).

**Aim:** To assess the efforts of psychosocial support to patients of nodding diseases in improving their sustainability

**Methods:** Mixed methods were employed in assessing the efforts of psychosocial support to patients of nodding disease and HIV. Assessment interviews were held with each selected household using a Household Assessment Tool (HAT). Further interviews were conducted using child status index, OVC monitoring tool and medical treatment summary form. Community dialogue meetings were done with child protection committee members and OVC caregivers. The data was entered into an MS- Excel Spread sheet and was analysed using pivot tables. It was as well complimented with MS-Access.

**Results:** The results of TASO's efforts toward sustainability were clustered within food security and nutrition, care and support, economic security and education support.

**Education support:** Scholastic materials were provided to a total of 50 households.

**Economic Security:** TASO also enabled these OVC households to attain support in joining micro-finance and small credit services at community level.

**Food security and nutrition:** Assorted vegetable seeds such as cabbages, onions and egg plants were distributed to a total of 50 households.

**Care and support:** TASO's initiatives were also directed towards provision of safe water vessels, blankets and beddings to elderly households affected by the nodding disease in Odek Sub County.

**Conclusion:** Whereas efforts towards the aetiology of nodding disease are central, important aspects of psychosocial support towards sustainability should be taken into consideration. OVC households need to be trained on management of micronutrient deficiencies.

## 5. CATATONIA IN UGANDAN NODDING SYNDROME AND EFFECTS OF LORAZEPAM TREATMENT.

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**Background:** Nodding Syndrome is a severe neuropsychiatric syndrome affecting children and adolescents in Northern Uganda yet its etiology and treatment are elusive. The symptoms of Nodding Syndrome and catatonia seem to overlap. Catatonia occurs in children and adolescents and its primary treatment is benzodiazepines, especially lorazepam.

**Objective:** We investigated the presence and types of catatonic symptoms in Nodding Syndrome and their response to one or two doses of lorazepam, the first-line treatment for catatonia.

**Design/methods:** Systematic assessment of catatonia in 33 patients with Nodding Syndrome. Observational study of catatonia in 16 patients who met criteria for catatonia. Open and uncontrolled study to examine the effects of one or two doses of lorazepam on catatonia in these patients.

**Results:** Sixteen of 33 patients with Nodding Syndrome had an average of 5 catatonia symptoms and met criteria for catatonia. The highest scores were found for mutism, staring, poor eating/drinking, stupor, and grimacing. In 6 children, there was a reduction of more than 50% in catatonia ratings, representing a positive response. Three out of 6 children whose catatonia ratings did not change after the first dose, responded after administration of a second double dose. There were no unusual or critical side-effects.

**Conclusions:** About half of the children with Nodding Syndrome met criteria for catatonia. Catatonia scores decreased in most patients after one or two doses of lorazepam. Larger, longer, and controlled studies are warranted.

## 6. CLINICAL EPIDEMIOLOGICAL ASPECTS OF EPILEPSY AT THE GENERAL HOSPITAL JASON SENDWE, LUBUMBASHI, R.D. CONGO.

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**Introduction:** Epilepsy is a serious public health problem in sub-Saharan Africa and particularly in DR Congo. In an effort to improve our understanding of this condition and to assist patients suffering from it, we have compiled records of patients admitted with the diagnosis of epilepsy at Jason Sendwe General Hospital (JGHH) in the city of Lubumbashi in the DR Congo over a period of 5 years.

**Methodology:** This work is a retrospective study. It covers a period of 5 years, from 01 July 2006 to 30 June 2011. The study population concerns patients admitted to the Neuropsychiatry Department of the Jason Sendwe General Hospital for an epileptic seizure. The parameters used in our study were: age, sex, commune of provenance, occupation, history of previous crises, characteristics of seizures, drugs used, duration of hospital stay and evolution. The analysis of the data was made using the software Epi Info 7 French version using the software IBM SPSS 19.

**Results:** Of the 183 epileptic patients admitted to the JGHH during the period mentioned in the methodology, the age ranged from 10 to 60 years, with an average of 18.7 years. There are 64.5% of male patients for 35.5% of the female sex with a sex ratio of 1.8. The communes of Lubumbashi and Kampemba are the most represented with respectively 26.2% and 21.4% of epileptic patients. Schoolchildren and students constitute the most affected population with a rate of 32%. The average of previous crises is 2 per month. The Tonic-clonic seizures are noted in almost all cases. Anti-epileptic drugs used as monotherapy are Phenobarbital 42% and Depakine 24% of cases. The duration of stay is 2 weeks (14 days on average) and the evolution is good overall.

**Conclusion:** What can we learn from this retrospective study?

- The difficulty of carrying out clinical retrospective studies in our environments because of the inadequate quality of medical records.
- The high frequency of tonic-clonic seizures reflect their easy recognition and difficulty recognizing non-motor seizures.
- Lack of adequate electroencephalic exploration. On the basis of this study, one or more prospective studies in the same hospital are necessary to clarify the questions we are asking ourselves.

## 7. ONCHOCERCIASIS ASSOCIATED EPILEPSY AND BLACKFLIES IN THE DEMOCRATIC REPUBLIC OF THE CONGO (DRC).

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**Introduction:** A high prevalence of epilepsy has been reported in many onchocerciasis endemic areas.

**Aim:** To determine the prevalence of epilepsy in onchocerciasis endemic areas in the DRC and to determine the species complex of *Simulium* sp. transmitting onchocerciasis.

**Methods:** Between 2014 and 2017, epilepsy prevalence surveys were carried out in areas with a high level of onchocerciasis endemicity: 3 localities in the Bas-Uele, 24 in the Tshopo and 21 in the Ituri province. Blackfly larvae were collected from aquatic vegetation, rocks or crab bodies and adult flies by human landing catch or after incubation of mature pupa in emergence vials.

**Results:** Of 12, 408 people examined 407 (3.3%) were found to have a history of epilepsy. A high prevalence of epilepsy was observed in health areas in the 3 provinces: 6.8-8.5% in Bas-Uele, 0.8-7.4% in Tshopo and 3.6-6.2% in Ituri. Median age of epilepsy onset was 9 years. Different species of anthropophilic blackflies belonging to a vector complex were identified: *Simulium damnosum* in the Bas-Uele, *S. damnosum* and *Simulium neavei* in the Tshopo province. In Ituri, western shore of Lake Albert, despite active searching we were unable to identify the vector. *S. vorax* larvae were found in rivers but no flies were collected actively biting humans. The Lendu plateau is historically a *S. damnosum* focus but the Albert lake shore of Uganda was a *S. neavei* focus. It may be that deforestation lead to the disappearance of the Albert lake onchocerciasis focus, and that seasonality plays a crucial role in the maintenance of *Simulium* populations. In Logo health zone 55.9% of persons with epilepsy had *Onchocerca volvulus* positive skin snips but an OV16 serosurvey among children 8-9 years old showed a prevalence of 7.8%, suggesting that there is currently limited transmission of onchocerciasis.

**Conclusions:** The prevalence of epilepsy in onchocerciasis endemic regions in the DRC was 2-10 times higher than in most non-onchocerciasis endemic regions in Africa. Different species of blackflies are responsible for onchocerciasis transmission in the DRC and ecological modelling studies are ongoing to determine the risk factors under various complex ecological systems.

## 8. THE SOCIAL AND PSYCHOLOGICAL EFFECTS OF ONCHOCERCIASIS ASSOCIATED EPILEPSY ON RURAL PEOPLE IN NYANTONZI, MASINDI, UGANDA

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Epilepsy support association Uganda

**Introduction:** Nyantonzi sub county is found in Masindi district in Western Uganda. The area is surrounded by Budongo forest, a tropical rain forest infested by the black fly that is responsible for the spread of onchocerciasis. The Ugandan Ministry of Health has been treating this oncho using Ivermectine. Since a few years it has been found out that there is a high prevalence of epilepsy in the area and that many of the sufferers of oncho also suffer from epilepsy. Whereas treatment for oncho is available and free of charge, the treatment for epilepsy is irregular and hard to come by. Combining the treatment for both chronic conditions also causes many social challenges as some of the individuals have already lost their sight while there is biting poverty in the area

**Aim:** To highlight the challenges faced by the people who suffer from the two diseases and to attract the attention of researchers.

**Results:** There are many people living with oncho in this area that have already developed epilepsy.. By doing a simple interview, the patient can be able to confirm that they are already receiving treatment for oncho. The interaction of the two diseases causes immense physical pain as their skin itches and others have already lost sight. The burden of caring for two conditions has caused chronic and biting poverty as sufferers are unable to work and families spend heavily on treating especially the epilepsy. Medications for epilepsy are very irregular. Patients suffering from both conditions are highly stigmatised in the community

**Conclusion:** There is need for continuous health education the community to eradicate the two conditions. Publication of this information will attract the attention of researchers to this area. Epilepsy can be placed at a higher priority within the Ministry of Health and better medication can be availed in this region of the country.



## 9. CUMULATIVE DOSES OF IVERMECTIN AND SEIZURE CONTROL IN CHILDREN AND ADOLESCENTS WITH NODDING SYNDROME IN UGANDA

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**Introduction:** Nodding syndrome is a poorly understood neurologic disorder that has been associated with infection with *Onchocerca volvulus* and is thought to be part of the spectrum of the Onchocerca Associated Epilepsies. In Uganda, most affected persons reside in the northern districts. Here, since 2012, twice yearly Mass Drug Administration of Ivermectin has been implemented as part of Onchocerciasis control. We hypothesized that in nodding syndrome patients on antiepileptic therapy, increasingly better seizure control would be gained with cumulative doses of Ivermectin.

**Aim:** Examine the relationship between the number of doses of Ivermectin and seizure control in patients with nodding syndrome.

**Methods:** This is a cross-sectional study of patients with nodding syndrome. The study is nested within an ongoing trial 'Doxycycline for the treatment of nodding syndrome (NCT02850913)'. Participants are children ages 8 years or older fulfilling the WHO criteria for confirmed nodding syndrome. All have detailed clinical assessments including the number of seizures in the past month, and documentation of ivermectin use. They are also screened for Onchocerciasis using an IgG4-OV16 rapid test and the microfilaria density determined on skin-snip microscopy.

**Preliminary results:** To date, 91/154(59.1%) screened positive for *O.volvulus* and 13/154(8.4%) tested positive for microfilaria on skin-snip microscopy. Generalized tonic-clonic seizures were the most prevalent type of seizures. The mean number of ivermectin doses taken was 5.1(SD 3.4). There was a trend towards a decreasing number of seizures with increasing doses of ivermectin. The mean number of doses of ivermectin in participants without seizures was 6.0 (SD 3.1), was 5.3 (SD 3.7) in those with 1-4 seizures, 5.0 (SD3.6) for participants with 5 seizures or higher. The differences were not however significant.

**Conclusion:** This preliminary data suggests non-significant improvement in seizure control in patients with nodding syndrome on antiepileptic treatment with cumulative doses of Ivermectin. Completion of the larger study is awaited.

## 10. ASYMPTOMATIC *PLASMODIUM FALCIPARUM* MALARIA AND SEIZURE CONTROL IN CHILDREN AND ADOLESCENTS WITH NODDING SYNDROME

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**Introduction:** *Plasmodium falciparum* is epileptogenic and in sub-Saharan Africa, this parasitic infection is a leading cause of acute symptomatic seizures. In malaria endemic areas, asymptomatic infections are common but the impact of such infections on the burden of seizures, especially in patients with known seizure disorders, is unknown.

**Aim:** To examine the relationship between asymptomatic *P.falciparum* infection and seizure control in children with nodding syndrome.

**Methods:** This was a cross-sectional study of seizure control in patients with nodding syndrome receiving care in specialised centres in northern Uganda. The study is nested within an ongoing trial 'Doxycycline for the treatment of nodding syndrome (NCT02850913)'. The hypothesis is that asymptomatic *P.falciparum* infection is associated with poorer seizure control. Participants were all on antiepileptic drug therapy (sodium valproate) and had standardized assessments including the types and number of seizures in the previous month. Blood was drawn for *P.falciparum* HRP2 and participants testing positive for malaria also had thick blood smears examined to determine parasite density.

**Preliminary results:** A total of 143/214(66.8%) had malaria. Asymptomatic infections (no history of fever and temp<37.5°C) were seen in 74/214 (34.5%) and symptomatic infections in 69/214 (32.2%). Both infections were associated with poorer seizure control. In the past month, the median number of seizures in those with no infection was 2.0[IQR 1.0-3.5], it was 3.0 [IQR 2.0-6.0] in those with asymptomatic malaria, and 4.0 [IQR 2.0-7.5] in patients with symptomatic malaria,  $p<0.05$ . A dose response effect was also observed between the parasite density and number of seizures,  $r=0.39$ ,  $p=0.003$

**Conclusion:** In patients with nodding syndrome, both asymptomatic and symptomatic *P.falciparum* malaria infections are associated with poorer seizure control. Preventive and treatment intervention studies are recommended. Similar relationships may also be examined in other seizure disorders.

## 11. IMPLEMENTATION OF A COMMUNITY ENGAGEMENT PROGRAM IN THE PATHOGENESIS AND TREATMENT OF NODDING SYNDROME STUDY IN UGANDA

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**Introduction:** Community engagement (CE) is a key but often overlooked component for successful implementation of community-based studies and trials. The Nodding Syndrome (NS) study in Uganda seeks to examine if NS is a neuro-inflammatory disorder and whether doxycycline may be used as treatment. As part of this study, we initiated a CE program to support implementation.

**Aim:** To build dialogue between communities and the research team, help the community understand research, encourage participation, the objectives and procedures of the study, and adherence to the study interventions and schedules.

**Methods:** Between August 2016 and January 2017, the study team worked with four communities, five health facilities and the leadership of Kitgum and Pader districts. We held dialogues on NS and the study with the community, health workers and district leaders and conducted focused group discussions with health workers and village health teams and interactive question and answer sessions with the communities.

**Results:** There was initial hostility towards research in NS and research scientists due to failure to feedback research results by previous research groups and the limited community participation in NS interventions. Affected persons felt abandoned. Since initiation of the CE, negative attitudes have reduced and there is increased willingness to participate in the study, positive feedback about the study team and excellent adherence to study medications and follow-up visits. The community is particularly positive about CE the process.

**Conclusion:** Community engagement has improved the community perceptions, uptake and participation in the study. We anticipate improvement in outcomes and the lessons learnt will be incorporated in future recruitments and studies.

## 12. ONCHOCERCIASIS-ASSOCIATED EPILEPSY AND ADHERENCE TO COMMUNITY DIRECTED TREATMENT WITH IVERMECTINE IN AN ONCHOCERCIASIS ENDEMIC HEALTH DISTRICT OF MASIMANIMBA IN THE DEMOCRATIC REPUBLIC OF THE CONGO

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**Introduction:** Ivermectin is a highly effective microfilaricidal that contributes to significant reduction of microfilarial load in infected *Onchocerca volvulus*. Because of this, transmission of onchocerciasis is also reduced significantly although its interruption does not occur as early as this treatment. Several studies revealed in predominantly endemic onchocerciasis areas, a higher prevalence of Onchocerciasis Associated Epilepsy (OAE) compared to areas under Community Directed Treatment with Ivermectin (CDTI). Some authors suggested that control of onchocerciasis with CDTI would contribute to decrease occurrence of seizure in OAE patients. Therapeutic adherence remains a major public health problem. Few patients with chronic diseases are genuinely adherent. This feature would be even lower in developing countries like the Democratic Republic of Congo.

**Aim:** To bring out influence of therapeutic adherence to CDTI on OAE and occurrence of seizures

**Methods:** It will be carried out over a total period of two months, a cross-sectional household survey in the Masimanimba Health District, located in the Province of Kwilu. Onchocerciasis cases will be actively screened during a household screening at the village level through a rapid diagnostic test of *O. volvulus* 16. This screening will be coupled with the detection of active cases of epilepsy and CDTI adhesion. For epilepsy detection, a questionnaire for investigation of epilepsy in the tropical environment will be used. Adherence to CDTI will be assessed by self-assessment (Morisky's indirect method) as a response to a carefully designed set of questions. An overall score after self-reassignment is awarded according to whether they are adherent or non-adherent.

**Results:** It is expected a strong positive influence of therapeutic adhesion in occurrence of seizures in OAE.

**Conclusion:** Expected results could pledge in favour of educational strategies promoting CDTI in onchocerciasis endemic areas in order to attain more adhesion.

### 13. ENTOMOLOGICAL INVESTIGATION AND GEOGRAPHIC DISTRIBUTION OF *SIMULIUM SPP.* BLACKFLIES IN RELATION TO NODDING SYNDROME IN NORTHERN UGANDA

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**Introduction:** Nodding Syndrome (NS) is a neurological disorder that is prevalent in localized foci. NS is associated with onchocerciasis endemic regions and may be caused by an autoimmune reaction to the parasitic worm, *Onchocerca volvulus*, which causes onchocerciasis. There is a need to further investigate the potential role that *Simulium spp.* blackflies, the vector that transmits *O. volvulus*, may play in the transmission of NS

**Aim:** The purpose of the study was to measure how potential biological and ecological risk factors contribute to the presence of *Simulium spp.* blackflies in the northern region of Uganda.

**Methods:** Blackfly collections were performed in 2 districts where previous cases of NS have been reported (Kitgum and Lamwo) and 3 districts where no NS cases have been reported (Nwoya, Moyo, Adjumani). Esperanza Window Traps were used to collect the blackflies and were placed by rivers, gardens, and animal corrals. Pathogen detection for *O. volvulus* was performed through PCR analysis. An ecological niche model created with Maxent utilized sites of the known blackflies locations in conjunction with environmental data layers to model predictive niches of the vector in the region of northern Uganda.

**Results:** Results indicated that there was a significant difference in the median number of blackflies collected in the animal corrals between districts where NS was present versus absent. The environmental variables that contributed the most to the predictive model were normalized difference vegetation index (NDVI), land cover, distance from rivers, and annual mean temperature.

**Conclusion:** Furthermore, the predicted high probabilities of *Simulium spp.* blackflies in this model could potentially be a useful tool in vector surveillance efforts and public health planning for NS and onchocerciasis.

## 14. ONCHOCERCIASIS-ASSOCIATED NEURODEVELOPMENTAL DEFICITS: THE HIT SQUAD

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**Introduction:** New challenges in neuroinfections arise as recent studies point out to a possible etiological role for onchocerciasis in epilepsy.

**Aim:** To elucidate the degree of association between epilepsy associated neurodevelopmental deficits (ENDD) and onchocerciasis in Congolese children recruited from a community subjected to mass treatment with ivermectin

**Methods:** A multidisciplinary team carried out studies using SMART (standardized monitoring and assessment of relief and transition) methodology for nutritional assessment and KABC-II testing batteries for cognition in Congo-Kinshasa. Skin biopsies were used to confirm *Onchocerca*-infection. Plasma cytokines were measured using the Human cytokine magnetic 30-plex (Life Technologies, CA).

**Results:** Fifty-one and five percent of households were experiencing food insecurity with 59.5 % (54.3 – 64.5) of children with stunted growth. Of the 130 subjects from a case-control study, 91 (70%) [mean age (SD): 23.2 (8.4) years] reported having epileptic seizures. Logistic regression indicated that epilepsy was associated with onchocerciasis [OR: 4.42 (1.97 – 9.91),  $p < 0.01$ ] and family history of epilepsy [OR: 5.72 (1.83 – 17.9),  $p < 0.01$ ]. Epilepsy was also associated with poor cognition in all domains of memory, learning, and planning; and levels of growth factor EGF and IL-8. Poor memory was associated with early onset of epilepsy, stunting, and levels of growth factors and/or cytokines notably RANTES ( $\rho = -0.35$ ,  $p = 0.01$  with memory KABC-II scores) or G-CSF ( $\rho = -0.42$ ,  $p = 0.04$ ) in onchocerciasis subjects

**Conclusion:** The pathogenesis of ENDD in onchocerciasis-area is multifactorial. Neurocognitive deficits may be mediated by inflammation and/or chronic malnutrition.

## 15. FIRST EVIDENCE BY A COHORT STUDY IN CAMEROON THAT ONCHOCERCIASIS DOES INDUCE EPILEPSY

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**Introduction:** Previous meta-analyses on the relationships between onchocerciasis and epilepsy were conducted both at community level (assessing the relationship between the prevalences of both conditions in a number of villages) and individual level (comparing the proportion of individuals infected with *Onchocerca volvulus* (Ov) among people living with epilepsy, PWE, and among controls). Both approaches suggested that onchocerciasis and epilepsy are closely associated. A single quantitative case-control study in Cameroon also showed that PWE had 2-3-fold higher Ov microfilarial (mf) densities than controls matched on sex, age and place of residence. To tackle criticisms about the fact that previous studies were cross-sectional, and that confounding factors might explain the relationship, we assessed, using a retrospective cohort study design, the incidence of epilepsy according to the initial Ov mf density measured during childhood.

**Methods:** Surveys on onchocerciasis with individual quantification of microfilaridermia were conducted in 1991-1993 on subjects aged  $\geq 5$  years living in  $>20$  villages of the Mbam valley (Cameroon). In 2017, seven villages with variable onchocerciasis endemicity levels were revisited to get information on the 858 children aged 5-10 years who had been examined in these communities in the 1990's. Information on the present vital status (alive vs. dead) and on the occurrence of epilepsy after the initial parasitological survey was collected from key informants, the subjects themselves or from the family, using a standardized "5-questions" questionnaire. Multivariable analyses taking into account age, sex, initial individual mf density, and transmission level, were conducted.

**Results:** In 2017, the proportions of targeted subjects for whom information was available from key informants or from the family were 90.0% and 85.2%, respectively. The overall incidence rate of epilepsy was 3.1 per 1000 person/year. The incidence rate decreased with age, but not significantly, and was significantly higher in villages with the higher Ov transmission level. The individual mf densities during the initial parasitological survey were very significantly associated with the occurrence of epilepsy, with incidence rate ratios of 9.4, 13.0 and 27.8 for subjects with initial mf intensity of 1-25, 26-129 and  $>130$  mf/2 skin snips, respectively, when compared with children without skin mf ( $P < 0.015$ ,  $< 0.001$  and  $< 0.001$ , respectively).

**Conclusion:** Individual Ov mf intensity at childhood was found to be strongly associated with the risk of epilepsy in an onchocerciasis focus in Cameroon, suggesting that the association between onchocerciasis and epilepsy is due to a direct effect of the parasite, and not to indirect phenomena involving auto-immunity.



## 16. EPILEPSY PREVALENCE AND COHORT AGE SHIFT: EVIDENCE FOR THE BENEFIT OF IVERMECTIN MASS DRUG ADMINISTRATION ON ONCHOCERCIASIS-ASSOCIATED EPILEPSY IN THE MBAM VALLEY, CAMEROON.

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**Introduction:** High prevalences of epilepsy and high intensity of infection with *Onchocerca volvulus* were recorded in surveys conducted in the Mbam Valley, Cameroon, in 1991-1993 (Boussinesq, 1992). Community-directed treatment with ivermectin initiated in 1998 in this area had a significant impact on the transmission of onchocerciasis. The present study aimed at investigating whether this led to a decrease in the epilepsy prevalence in the area.

**Methods:** A door-to-door household survey was conducted in July 2017 in three villages of the area where a census of people living with epilepsy (PLE) was performed in 1991 (Bayomen, Ngongol, and Nyamongo). Following information and written consent from the heads of the household, a validated 5-items questionnaire for epilepsy screening was administered to the whole population (Quet et al, 2011).

**Results:** Three-hundred and nineteen households were screened, contributing for a total of 2168 individuals (566 in Bayomen, 517 in Ngongol, and 1085 in Nyamongo). The overall prevalence of suspected epilepsy in 2017 was 4.9% (n=107). Between 1991-1993 and 2017, epilepsy prevalence decreased from 13.6% to 2.5% in Bayomen (p=0.001), from 8.7% to 6.6% in Ngongol (p=0.335) and from 6.4% to 5.4% in Nyamongo (p=0.418). However, the median age of individuals with epilepsy increased from 16 years (interquartile range [IQR] 13-21) in 1991-1993 to 24 years (IQR 19-33) in 2017 (p<0.001). In 2017, only 6 (5.6%) suspect cases were younger than 10, while 30 (28.0%) were aged between 10 and 20 years, and 71 (66.4%) were older than 20. 21 (0.97%) persons were diagnosed with head nodding seizures and one person with Nakalaga syndrome was observed.

**Conclusions:** A slight decrease in epilepsy prevalence was observed between 1991-1993 and 2017, following 18 rounds of ivermectin mass drug administration (MDA). However, a dramatic decrease occurred in Bayomen, a village where ivermectin distribution was strongly supported by the local authorities themselves. In addition, the age distribution of people with epilepsy differed markedly between 1991-1993 and 2017. This age shift is consistent with a recent decrease in epilepsy incidence and supports the hypothesis that ivermectin MDA reduced the burden of onchocerciasis—associated epilepsy in this initially highly endemic area.

## 17. AGE SHIFT OF PERSONS WITH EPILEPSY IN BILOMO, CAMEROON, FOLLOWING IVERMECTIN MASS DRUG ADMINISTRATION FOR ONCHOCERCIASIS. JULY 2017

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**Introduction:** The prevalence of epilepsy [Nodding Syndrome (NS) not assessed] in Bilomo village in the Mbam valley, Cameroon was estimated at 4.9% in 1998 (Njamnshi et al. 2000). This area is endemic for onchocerciasis, a condition associated with epilepsy. Following government intervention of yearly ivermectin Mass Drug Administration (MDA) in the Mbam area for over fifteen years, the present research aimed at testing the hypothesis that the prevalence or incidence of epilepsy would significantly reduce in Bilomo following ivermectin MDA and determining the prevalence of NS.

**Methods:** A door-to-door household survey was carried out from July to September 2017, during which resident members of each household were screened. Those with a history of seizures underwent a neurological evaluation and general clinical examination for burns and bruises from epilepsy by a team of neurologists and dermatologists. Those suspected of Nodding Syndrome were further assessed using video-EEG in the Neurology Department of the Yaoundé Central Hospital. Data from the current study were compared with data obtained during a similar survey performed in 1998. Ethical and administrative authorizations were obtained from respective institutions.

**Results:** Of the 1321 individuals screened in 193 households from 8 quarters of Bilomo village, 61 had epilepsy (prevalence: 4.6%) and 9 others had probable NS (prevalence: 0.68%). The age range was 0-94 years (mean: 23.8±20.3 years) and 27.80% were between the age 10 to 19 years old in 2017 compared to 60.21% in 2000 ( $p = 0.001$ ). Furthermore, concerning the older age group of 20-34 years, this category constituted 60.7% of PWE in 2017 compared to only 34.41% in 1998 ( $p = 0.001$ ).

**Conclusions:** After 20 years following the first survey and after 15 years of ivermectin MDA the prevalence of epilepsy in Bilomo remained unchanged 4.6% in 2017 compared to 4.9% in 1998. However, a significant age shift of the epilepsy cases towards the older age groups was observed. Considering that the age distribution of the population has not changed significantly, this may suggest a decrease in the incidence of epilepsy in the 10-20 age group potentially caused by ivermectin MDA. Finally, Nodding Syndrome may be a neglected form of epilepsy in this area.

## 18. OUTPATIENT ATTENDANCES FOR EPILEPSY IN ONCHOCERCIASIS ENDEMIC AND NON-ENDEMIC DISTRICTS OF UGANDA: AN ANALYSIS OF THE 2012-2015 NATIONAL HEALTH MANAGEMENT INFORMATION SYSTEM DATA.

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**Introduction:** Epidemiological studies have repeatedly reported an association between epilepsy and onchocerciasis. Previous research on epilepsy and onchocerciasis in Uganda has been limited in scope, size and geographical coverage. We analyzed the 2012 – 2015 national Health Management Information System (HMIS) data and compared outpatient department (OPD) attendances for epilepsy between districts of differing onchocerciasis transmission status.

**Material/methods:** An ecological time-series analysis of 154,650,873 OPD attendances from July 2012 to June 2015 in 112 Ugandan districts was performed. Epidemiological onchocerciasis mapping from the Uganda Ministry of Health (MOH) Vector Control Division and the Carter Center was used to categorize Ugandan districts into three onchocerciasis transmission groups: 1) non-endemic/eliminated, 2) transmission interrupted and 3) transmission ongoing. A one-way ANOVA test was conducted to compare the mean proportion of OPD attendances for epilepsy between the different onchocerciasis transmission groups. A multivariate time series analysis was also performed to describe trends in monthly OPD attendances for epilepsy in each of the onchocerciasis transmission groups.

**Results:** Between 2012 and 2015, the mean proportion of OPD attendances for epilepsy in districts with ongoing onchocerciasis transmission was 1.23% and was significantly higher than in the districts where onchocerciasis was interrupted (0.66%,  $p<0.001$ ) or non-endemic/eliminated (0.56%,  $p<0.001$ ). A statistically significant adjusted declining monthly trend was observed in districts with ongoing transmission ( $-0.088$ ,  $p=0.020$ ) and an adjusted increasing monthly trend was observed in districts where onchocerciasis is non-endemic/eliminated ( $0.019$ ,  $p=0.036$ ). The trend in the transmission interrupted group was not statistically significant ( $0.007$ ,  $p=0.662$ ).

**Conclusions:** These results strengthen the evidence of an association between epilepsy and onchocerciasis. The rising trend of proportion of OPD attendances for epilepsy in districts where onchocerciasis is non-endemic or has been eliminated needs further investigation. Further epidemiological, clinical and pathophysiological studies should be conducted to establish how onchocerciasis may cause epilepsy.

## 19. THE GENDERED BURDEN OF NODDING SYNDROME IN CAMEROON, TANZANIA AND UGANDA

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**Introduction:** Evidence suggests that there is a higher occurrence of epilepsy in onchocerciasis endemic areas in Central and Eastern Africa, usually considered to be nodding syndrome (NS) or onchocerciasis-associated epilepsy (1,2). Treatment for NS/epilepsy in these areas only alleviates the symptoms as there is no cure. The consequences of the disease such as unpredictable seizures and cognitive decline lead to stigma, and dependency on other household members that have a significant impact on the psycho-social well-being and daily subsistence of affected households.

**Aim:** To assess the social impact of the disease burden of NS at the household level in Northern Uganda, Central Cameroon and Southern Tanzania.

**Methods:** Ethnographic research was carried out in 13 villages in Uganda, 11 villages in Cameroon, and 11 villages in Tanzania. Data-collection consisted of participant observation, informal conversations, in-depth interviews and focus group discussions. Sampling was theoretical. Data analysis was deductive and concurrent to data collection and carried out using NVivo 11 Qualitative Data Analysis software.

**Results:** In all 3 study countries, women of all ages carry a disproportionate burden of diseases both as epilepsy patients and as caretakers. Young girls/children and female adolescents affected by epilepsy are expected to continue with household chores that involve proximity to fire and water and are consequently more at risk for burns and drowning as compared to male patients. Furthermore, they are more vulnerable to sexual abuse, consequent unwanted pregnancies and are responsible for the care of small children without the financial and moral support, thereby limiting their own and their children's access to health care. In case an epilepsy patient, including young mothers, suffer from cognitive decline the care of her children again falls to other female relatives, such as the mother or grandmother.

**Conclusion:** Long-term debilitating diseases, as is the case for NS, might result in a gendered disproportionate burden on women, causing them to spiral deeper into poverty. A more context-specific tailored approach should support women and tackle the conditions of their vulnerability, such as the economic burden of caretaking and psycho-social distress.

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## 20. ONGOING ONCHOCERCIASIS TRANSMISSION AND HIGH PREVALENCE OF EPILEPSY DESPITE 19 YEARS OF MASS DISTRIBUTION OF IVERMECTIN IN THE MBAM VALLEY, AN ONCHOCERCIASIS-ENDEMIC REGION IN CAMEROON.

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**Introduction:** Recent progress in onchocerciasis control has led to the concept and strategy of elimination of the disease. Despite 19 years of ivermectin use, a high prevalence of epilepsy was still observed in villages in the Mbam valley in Cameroon. In this study we aimed to determine the degree of ongoing onchocerciasis transmission by IgG4 *Onchocerciasis volvulus* (Ov) antibodies of children 7-10 years old. We also determined the prevalence of Ov antibodies in persons with epilepsy (PWE).

**Methods:** Testing for IgG4 antibodies using the Ov16 testing (SD Bioline Onchocerciasis IgG4, Standard Diagnostics Inc.) was performed in healthy children aged between 7 and 10 years and in PWE in Bilomo, a village in the Mbam and Kim Division in Cameroon, endemic for onchocerciasis. Screening for Ov antibodies was done by testing a finger-prick blood sample. Test results were read and interpreted according to manufacturer's indications but also checked after 20 minutes. Ethical and administrative authorizations were obtained from respective institutions.

**Results:** In a population of 1321 individuals we detected 61 (4.6%) PWE not including 9 (0.68%) suspected of Nodding syndrome. The healthy children group consisted of 145 individuals. 26(42.6%) PWE and 77(53.1%) healthy children tested positive on Ov-16 screening. Amongst the 9 suspected cases of nodding syndrome, 5 participants (55.6%) had a positive Onchocerciasis serology. There was no significant difference in Ov-16 seropositivity between nodding syndrome and the other forms of epilepsy ( $p=0.40$ ).

**Conclusion:** The high prevalence of Ov16 positivity in children 7-10 years old suggests a high degree of ongoing onchocerciasis transmission in the Mbam valley. The relatively low prevalence of Ov16 antibodies in PWE is surprising but may be related to the low sensitivity of the test and could be related to several years of ivermectin intake. Our results show that interventions to strengthen the onchocerciasis elimination programme in the Mbam valley are urgently needed.

## 21. ANXIETY AND DEPRESSION IN PEOPLE WITH EPILEPSY (PWE) LIVING IN AN ONCHOCERCIASIS-ENDEMIC REGION IN CAMEROON.

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**Introduction:** Epilepsy constitutes a major burden in sub-Saharan Africa where more than 80% of PWE live. In Cameroon, one of the major epileptic foci is the Mbam area, a zone equally endemic to onchocerciasis. Although mood disorders are known to be highly prevalent in PWE, contributing to a vicious cycle of poor adherence to AED treatment and poor seizure control, very little is known about this in Cameroon.

**Aim:** We therefore sought to study this comorbidity in a population of PWE living in an onchocerciasis-endemic region.

**Methods:** We carried out a community-based case-control study in Bilomo village, of the Mbam and Kim division, involving PWE and age- and sex-matched healthy controls using the Hospital Anxiety and Depression Score.

**Results:** A total of 40 cases and 40 controls were recruited with a mean age of 25.7 years. The prevalence of anxiety and depression were respectively 37% and 48% in the cases against 5% and 13% in the control group ( $p=0.002$ , CI [1.32 – 2.59] and  $p=0.002$  CI [1.32-3.30]). The factors associated with anxiety were; occurrence of the most recent seizure within past week and seizure frequency of more than once a month, while a longer duration of epilepsy was associated with lower anxiety rates. Conversely, high seizure frequency and a history of status epilepticus were associated to higher rates of depression.

**Conclusion:** Mood disorders are significantly more prevalent among PWE living in this Onchocerciasis endemic region. Poor seizure control and its complications are associated risk factors. Routine screening and optimal seizure control are necessary.

## 22. EPILEPSY-ASSOCIATED NEUROCOGNITIVE DISORDERS (EAND) IN AN ONCOCHERCIASIS-ENDEMIC REGION IN CAMEROON

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**Introduction:** Epilepsy affects approximately 43 million individuals in Sub-Saharan Africa. The focus of clinical care is directed at controlling seizures, neglecting other complications. Cognitive impairment is frequent in epilepsy causing poor academic performance, school dropout and unemployment.

**Objective:** Study Epilepsy-Associated Neurocognitive Disorders (EAND) in people living with epilepsy (PWE) in the Mbam Division, Cameroon.

**Methods:** This was a case-control study including PWE and age/sex-matched healthy controls from July to September 2017 in Bilomo village, Mbam and Kim Division. The Montreal Cognitive Assessment, International HIV Dementia Scale, Dubois' Five Word testing, Frontal Assessment Battery, Isaac's Set Test and the Clock test were administered to the study participants to evaluate global and specific cognitive functions.

**Results:** Eighty participants (40 cases and 40 controls) were included (mean age of 25.78 years). The prevalence of global cognitive impairment was 84.6% according to the IHDS among the cases against 40% for the controls ( $p = 0.000061$ ; OR 3.37; CI 1.60-7.07). The specific cognitive deficits were executive dysfunction (100% of cases vs 52% of controls  $p = <0,001$  OR = 1.52 CI 1.32 - 1.95) and decreased verbal fluency (100% of cases against 45% of controls  $p < 0.0001$ ; OR 1.82; CI 1.47-2.73). A longer duration of epilepsy and higher seizure frequency were associated with global cognitive impairment and antiepileptic drug use with poorer memory scores.

**Conclusion:** The prevalence of cognitive impairment is much higher in PWE in the Mbam particularly executive dysfunction and decreased verbal fluency. Longer disease duration, higher seizure frequency and antiepileptic treatment are associated with poorer cognitive performance.



## 23. THE INTERNATIONAL HIV DEMENTIA SCALE (IHDS) FOR COGNITIVE EVALUATION OF EPILEPSY PATIENTS LIVING IN AN ONCHOCERCIASIS-ENDEMIC REGION IN CAMEROON

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**Introduction:** Cognitive dysfunction is a frequent but seemingly neglected complication in epilepsy. Little data exist on the subject in Sub-Saharan Africa, particularly in Cameroon. A major obstacle is the absence of simple and culturally adapted tools for neuropsychological evaluation in rural populations. The objective of this study was to investigate the usefulness of the IHDS for cognitive screening in people living with Epilepsy (PWE) in the Mbam valley. The instrument assesses memory, motor and psychomotor speed which can all be altered in epilepsy. This 5min clinical tool can be applied in any context by a non-physician health professional.

**Methods:** We carried out a case-control study including PWE and age/sex-matched controls in the Mbam division. The performances of the IHDS and the Montreal Cognitive Assessment (MoCA) were compared in this population.

**Results:** The mean MoCA score in the case group was  $13 \pm 5.849$  against  $20.23 \pm 3.88$  for the healthy subjects  $p < 0.001$ . Considering the standard cut off of 26, the proportion of cases and controls with pathologic scores was not significantly different in both groups (97.5% against 82.5% for cases and controls respectively  $p = 0.057$ ). The mean IHDS scores were  $7.31 \pm 3.054$  and  $10.18 \pm 2.074$  for the cases and controls respectively  $p < 0.001$ . The prevalence of cognitive impairment based on the IHDS was 84.6% (using the standard 11 cut-off) for PWE against 40.0% for the healthy subjects, ( $p = 0.000061$ ; OR 3.37; CI 1.60-7.07).

**Conclusion:** The IHDS might be a better screening tool than the Classical MoCA for cognitive evaluation in PWE in rural populations.

## 24. PREVALENCE AND ANNUAL INCIDENCE OF NODDING SYNDROME AND OTHER FORMS OF EPILEPSY IN ONCHOCERCIASIS ENDEMIC AREAS OF NORTHERN UGANDA

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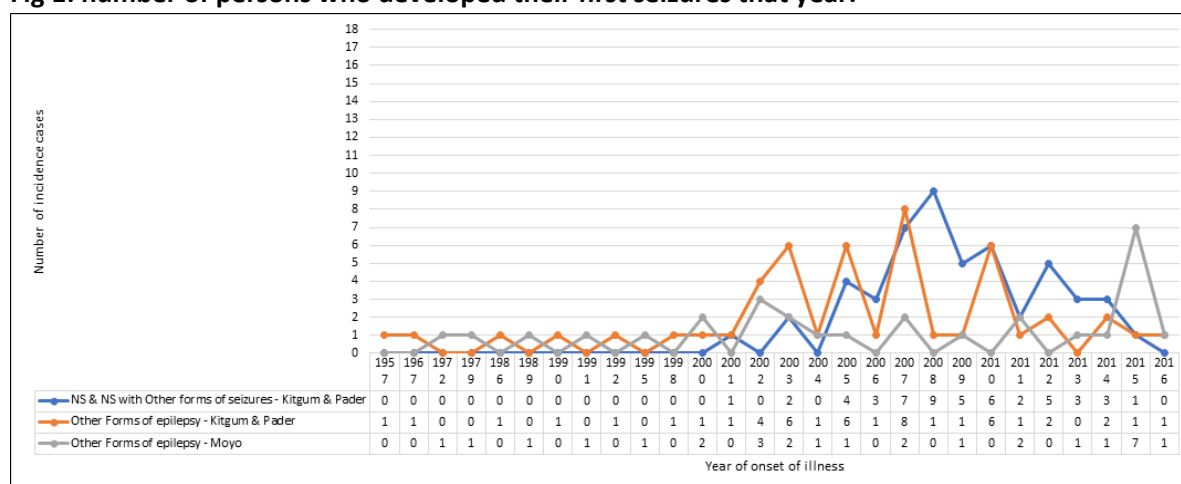
**Introduction:** Between 2000 and 2012, an outbreak of an epilepsy-like illness referred to as Nodding Syndrome (NS) occurred in following northern Ugandan districts of high onchocerciasis endemicity; Pader, Lanwo and Kitgum. Ivermectin distribution started only in 2007 but treatment coverage was initially sub-optimal. In 2012, the Government of Uganda conducted a census to document all cases of NS and other forms of epilepsy (OFE) and implemented bi-annual ivermectin Mass Drug Administration (MDA) and river larviciding in the affected districts. In 2017, we conducted a household survey seeking to establish the prevalence, and annual incidence of NS and OFE in northern Uganda.

**Methods:** A door-to-door household survey was carried out from August to September 2017, during which household members were screened in Kitgum and Pader and in the district of Moyo, an onchocerciasis endemic district which has implemented ivermectin MDA for more than 15 years. Those suspected to have epilepsy or NS underwent a neurological evaluation and general clinical examination to confirm the diagnosis of NS or OFE by a trained medical team. Data from the current study were compared with data obtained during the 2012 NS/epilepsy census.

**Results:** A total of 2,138 individuals from 381 households were screened for NS and OFE. In Kitgum and Pader the median age of all persons with epilepsy was 18 years (range: 2 – 70; mean 19±8.9) and in Moyo 23 years (range: 3 – 64; mean 26.6±16). During the 2012 census median age was of all persons with epilepsy was 13 years (range 1 – 93; mean 21.2±12). Prevalence of NS and NS with other forms of seizures was 2.4% (4.1% in Kitgum, 4.9% in Pader and 0% in Moyo) and that of OFE 4.4% (4.9% in Kitgum, 4.6% in Pader and 4.0% in Moyo).

In Kitgum and Pader, numbers of NS and OFE increased from 2000 to 2008 and decreased thereafter in a similar way. In Moyo the number of persons who developed epilepsy per year was relatively stable over time but peaked in 2015.

**Fig 1: number of persons who developed their first seizures that year.**



In 2012 in Kitgum and Pader, 72% of NS and 63% of OFE were 5-18 years old and 8.9% of NS and 6.6% of OFE was 19-30 years old. In contrast in 2017, 54% of NS and 36.8% of OFE was 5-18 years old and 40.2% of NS and 52.6% of OFE was 19-30 years old.

**Conclusions:** Following ivermectin MDA, there was a significant decrease in incidence of NS and OFE. The age shift over a 5-year period of persons with NS and OFE to older age groups is most likely explained by a decreased incidence in the 5-18-year-old age group and an increased survival because of increased access to anti-epileptic treatment. The similar epidemiological trends of NS and OFE suggests that NS and OFE share the same risk factors and etiological agent. The high number of OFE cases in Moyo seen in 2015 needs to be investigated.

## 25. EPIDEMIOLOGY OF ONCHOCERCIASIS AND EPILEPSY IN ITURI PROVINCE IN THE DEMOCRATIC REPUBLIC OF THE CONGO (DRC)

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**Introduction:** Many studies have suggested an association between epilepsy and onchocerciasis.

**Aim:** To determine the prevalence of epilepsy and to investigate whether an association exists between epilepsy and onchocerciasis in a rural population in Ituri Province, DRC.

**Methods:** In August 2016, a population-based cross-sectional study was conducted in the rural health zone of Logo, Ituri Province, an onchocerciasis endemic area without a history of ivermectin mass distribution campaigns. To identify cases of epilepsy, a three-stage approach was used. All individuals of 258 randomly selected households were screened for epilepsy by non-medical field workers using a validated 5-item survey. In a second and third stage, suspected cases of epilepsy were examined by non-specialist medical doctors and by a neurologist, respectively. A case of epilepsy was defined according to the International League Against Epilepsy guidelines. Exposure to onchocerciasis was assessed by detecting IgG4 antibodies to *O. volvulus* antigen (OV16 rapid test, SD Bioline, Inc) in individuals aged 3 years and older.

**Results:** Out of 1,426 censused household members, 82 (5.8%) were suspected of having epilepsy at 1<sup>st</sup> stage. 4(7.2%) of 55 suspected cases examined at the 2<sup>nd</sup> stage were not confirmed. 40 (91%) of 44 suspected cases examined at the 3<sup>th</sup> stage were confirmed having epilepsy. Because of missing data we cannot determine the exact prevalence of epilepsy but the prevalence must be at least 2.8% (40/1,426) (5 times higher than in most non-onchocerciasis endemic regions in Africa).

Of 915 individuals, for whom data was available on both OV16 testing and epilepsy, 40 (4.4%) were found to be confirmed cases of epilepsy. Median age of epilepsy onset was 12 years. Among confirmed epilepsy cases, OV16 positive test results were clustered by age-groups and locality, but not by gender. Age-adjusted OV16 positivity among persons with epilepsy was 1.6 times higher ( $p=0.022$ ) than among persons without epilepsy, respectively 47.5% (19/40) and 29.8% (261/875).

**Conclusion:** A high prevalence of epilepsy and a significant association between epilepsy and exposure to onchocerciasis was observed among the population of the Logo health zone in Ituri.

## 26. ONCHOCERCIASIS ASSOCIATED EPILEPSY IN THE ITURI PROVINCE IN THE DEMOCRATIC REPUBLIC OF THE CONGO: A CASE-CONTROL STUDY

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**Introduction:** A recent study reported that the prevalence of epilepsy in villages in onchocerciasis endemic areas in the Democratic Republic of the Congo (DRC) was 2-10 times higher than in non-onchocerciasis endemic regions in Africa. The WHO recommended strategy for the control of onchocerciasis is mass drug administration through community-directed treatment with ivermectin (CDTi).

**Aim:** This study investigated the relationship between onchocerciasis and epilepsy in endemic regions for onchocerciasis in DRC

**Methods:** In October-December 2015, a case-control study was performed in 3 rural health zones (RHZ) in DRC: RHZ Rethy (3 CDTi campaigns before study) and RHZ Logo (no CDTi), Ituri Province; RHZ Wanierukula (13 CDTi campaigns), Tshopo Province. Individuals who developed unprovoked convulsive epilepsy of unknown aetiology 12 months before the study were enrolled as cases (n=172). Controls (n=168) were randomly selected healthy members from the same village and age-groups as the cases. A validated questionnaire was used to collect sociodemographic, clinical, and neurological data. Physical and neurological examinations were performed by a physician and neurologist, respectively. Current infection with *Onchocerca volvulus* was assessed through detection of microfilariae in skin snip biopsies. Exposure to onchocerciasis was assessed by serology-based rapid tests (SD BIOLINE) detecting human OV IgG4 antibodies.

**Results:** In the RHZ Logo, onchocerciasis associated symptoms (e.g., itching and abnormal skin) as well as epilepsy indirectly related morbidity (e.g., burn scars) were more often present in cases compared to controls (respectively, OR=2.93, 95%CI(1.34,6.40), p<0.01 and OR=23.53, 95%CI(5.25,105.38), p=0.000). Furthermore, skin snip positivity (55.9% vs 25.8%, OR=3.66, 95% CI (1.72,7.78), p<0.0006) median number of microfilariae (56 vs 2), and presence of OV IgG4 antibodies (OR=3.35, 95%CI(1.54,7.32), p<0.002) were significantly higher in cases compared to controls. In general, persons with epilepsy were 2.71 times more likely to be onchocerciasis positive compared to controls (95%CI (1.73,4.25), p<0.0001).

**Conclusion:** The outcome of this study corroborates with the growing body of literature reporting a strong association between epilepsy and onchocerciasis in poorly controlled onchocerciasis endemic regions in Africa.

## 27. CLINICAL PRESENTATION OF EPILEPSY IN FOUR VILLAGES IN AN ONCHOCERCIASIS ENDEMIC AREA IN MAHENGE, TANZANIA

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**Introduction:** The Mahenge mountains in the Ulanga district in Tanzania is an onchocerciasis endemic area whereby the national Onchocerciasis control programme introduced the community directed treatment with ivermectin (CDTI) since 1997. In 1989, in one rural village in the area, in a very high prevalence of epilepsy (3.7%) was reported. Moreover, children with epilepsy and nodding of the head were first described in the area in 1950.

**Aim:** To describe the clinical presentation of epilepsy in villages known to have a high prevalence of epilepsy in the Mahenge area.

**Methods:** In January 2017, in 2 rural and 2 semi-urban villages, a door to door survey was conducted by community health workers using a 5 questions validated screening questionnaire to identify patients with suspected epilepsy. Persons with suspected epilepsy were then examined by a neurologist. A person was considered to have confirmed epilepsy using the International League Against Epilepsy criteria for epilepsy. Epilepsy suspected individuals were tested for antibodies against *Onchocerca volvulus* IgG4 antigen using the Ov16 test (OV16 rapid test, SD Bioline, Inc).

**Results:** Out of 210 epilepsy suspected individuals, 106 (50.5%) were confirmed to be epileptic. The prevalence of epilepsy in the village with the highest prevalence of epilepsy in 1989 was still high (2.7%). Of epileptic patients, 85(80.2%) knew that they were epileptic and their median age of seizure onset was 12 years (Interquartile range 8 -16). 60 (56.6%) of all seizures were generalized tonic-clonic. Other forms of seizures included atonic seizures 13.2%, absences 7.5%, simple partial 1.9% and complex partial seizures 2.8%, secondarily generalized partial seizures 6.6%. A history of head nodding was reported in 23 (21.7%)(5.6% with past history and 16% present). In 27 (25.5%) there was a family history of seizures. One person (male, 19 years old, 34kg body weight and 142cm height) presented with Nakalanga syndrome features.

**Conclusion:** The peak onset of epilepsy between the ages of 3 to 20 years is a characteristic of onchocerciasis association epilepsy. Nodding syndrome, Nakalanga syndrome and other forms of epilepsy were observed in the same villages.

## 28. NODDING SYNDROME IS PREVENTABLE

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**Introduction:** A link between nodding syndrome (NS) and onchocerciasis has been suspected based on case control studies performed in northern Uganda and South Sudan.

**Aim:** To investigate whether ivermectin could protect against epilepsy in an onchocerciasis endemic region.

**Methods:** A transdisciplinary project (NSETHIO) was created to investigate NS and epilepsy in onchocerciasis endemic areas in 5 African countries: the Democratic Republic of the Congo (DRC), Uganda, Tanzania, South Sudan, and Cameroon. In the DRC, between 2014-2016, house-to-house epilepsy prevalence surveys were carried out in areas with a high level of onchocerciasis endemicity: in 3 localities in Bas-Uele, 24 in Tshopo and 21 in Ituri province. Ivermectin uptake was recorded for every household member. A case of epilepsy was defined as a patient who reported at least 2 unprovoked seizures without fever or any acute illness. This database allowed a village, age and gender matched case-control pair subset to be created that enabled putative risk factors for epilepsy to be tested using univariate logistic regression models.

**Results:** In the DRC, of the 12,408 people examined 407 (3.3%) were found to have a history of epilepsy. Median age of epilepsy onset was 9 years. A case control analysis of 96 cases and 96 controls demonstrated that before the appearance of epilepsy, compared to the same life period in controls, persons with epilepsy were less likely (OR: 0.52; 95%CI: (0.28, 0.98)) to have taken ivermectin than controls. Surveys in South Sudan, northern Uganda and Tanzania showed that persons with NS and persons with other forms of epilepsy clustered in villages with high ongoing onchocerciasis transmission. In the majority of these individuals the onset of epilepsy was between the ages of 3 to 18 years. In northern Uganda the NS epidemic stopped after the introduction of mass ivermectin distribution and larviciding rivers. Meanwhile in South Sudan, with interruption of ivermectin distribution, new cases of NS continue to appear. Epilepsy survey data from Uganda and Cameroun (where larviciding rivers was never implemented) will be presented at the conference.

**Conclusions:** Strengthening onchocerciasis elimination programs is the way forward to prevent the development of NS in children.

## 29. HIGH PREVALENCE OF EPILEPSY AND ONCHOCERCIASIS AFTER 20 YEARS OF IVERMECTIN USE IN FOUR VILLAGES OF THE MAHENGE AREA IN TANZANIA

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**Introduction:** A high prevalence of epilepsy has been reported in many onchocerciasis endemic regions. Nodding syndrome, a distinctive form of epilepsy has been reported to occur also only in onchocerciasis endemic regions. Although epidemiological studies underline the association between onchocerciasis and the onset of epilepsy, the causative mechanism is not yet understood.

**Aim:** To determine the prevalence of onchocerciasis, and prevalence and incidence of epilepsy following long-term use of ivermectin in control of onchocerciasis in the Mahenge area of the Ulanga district in Tanzania.

**Methods:** The study was conducted in two rural and two semi-urban villages near Mahenge township in the Ulanga district. These villages, particularly the rural ones had been found to have a high prevalence of epilepsy during a survey in 1989. January 2017, we performed a door-to-door epilepsy survey using a 5 questions validated questionnaire, Persons with a positive answer to one of the questions were seen by a neurologist. Clinical, neurological and laboratory examinations were performed in all epilepsy suspects. We also tested children 7-10y old for the presence of *Onchocerca volvulus* (OV) antibodies and performed a rapid epidemiological mapping of onchocerciasis (REMO).

**Results:** 5160 (median age 18.5y, 47.8% male) individuals from 1172 households were registered. 264 (5.1%) individuals were suspected to have epilepsy during screening and 2.04% were confirmed to have epilepsy, 2.84 % in the rural vs 1.32% in the semi-urban villages,  $p < 0.001$ . The incidence of new onset epilepsy was 63.8 per 100,000 persons/y.

In children 7-10 y old the prevalence of OV16 positivity was 42.6% in the rural and 4.7% in the semi-urban villages,  $p < 0.001$ . Among men > 20 years old the prevalence of OV16 positivity was 65% and 1.8% were found to have onchocerciasis nodules.

**Conclusion:** Despite the use of ivermectin for about 20 years, the prevalence of onchocerciasis and epilepsy remains high in the two rural villages the Mahenge area with no substantial change in the incidence and prevalence of epilepsy compared 1989. These findings suggest a suboptimal functioning of the onchocerciasis control programme. Reasons for persistence of onchocerciasis and epilepsy needs further investigations and strengthening of the onchocerciasis control programme.



### 30. COMMUNITY-BASED PERCEPTIONS OF IVERMECTIN IN THE SANAGA BASIN OF CAMEROON

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**Introduction:** Evidence suggests that there is an association between onchocerciasis (river blindness) and epilepsy. In Cameroon, ivermectin (IVM) distribution programmes to treat (and protect) communities affected by onchocerciasis have been on-going in the Sanaga basin for almost 20 years.

**Aim:** To assess perceptions and uptake of (IVM) and its distribution programme at community level in an area of high prevalence of epilepsy in Cameroon

**Methods:** Ethnographic research was carried out in 10 onchocerciasis-endemic villages in the Mbam valley of the Sanaga basin in Cameroon using participant observation, informal conversations, in-depth interviews and focus group discussions. Sampling was theoretical and data analysis was concurrent to data collection and carried out using NVivo 10.

**Results:** Several barriers to the uptake of IVM were identified. The conduct of IVM distribution varied from village to village and not all eligible individuals were offered treatment or visited door-to-door. In villages with incentives for community distributors, coverage was better according to community participants' accounts. IVM uptake was compromised mainly by fear of side effects like body swelling that prevented people from working and even death, and conversely by the lack of perceived benefits as people feel healthy. Despite these barriers, according to community members' accounts, continuous sensitization, especially radio sensitisation, seemed to have had a positive impact, improving attitudes towards IVM uptake. Most people have basic knowledge about IVM and its purpose (filaria treatment).

**Conclusion** IVM uptake can be improved by periodic sensitisation campaigns to erase any misconceptions or rumours that may arise. It should also be complemented by ensuring that migrants and all residents of a village are visited door-to-door and there is observed administration of medicine. Additionally, sustainable incentives like community assistance in farming for community drug distributors would serve as motivation and improve reliability of drug distribution.

### 31. EPILEPSY PERCEPTIONS AND EXPERIENCES OF DIFFERENT STAKEHOLDERS PRIOR TO THE IMPLEMENTATION OF AN EPILEPSY TREATMENT PROGRAMME IN AN ONCHOCERCIASIS ENDEMIC REGION IN ITURI, DEMOCRATIC REPUBLIC OF THE CONGO (DRC)

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**Introduction:** Recent surveys in villages in onchocerciasis endemic regions in the DRC (Bas Uélé, Tshopo and Ituri) showed a prevalence of epilepsy 5-10 times higher than in most other non-onchocerciasis endemic regions in Africa. These surveys revealed that the majority of the persons with epilepsy were not treated. In Africa epilepsy case management is challenging, particularly in onchocerciasis endemic regions where there is a lack of well-trained health care workers. The success of an epilepsy treatment program will depend on the knowledge, engagement and acceptability of all the stakeholders.

**Aim:** Prior to the implementation of a system to treat persons with epilepsy in Ituri we investigated the knowledge, attitudes, and perceptions about epilepsy in two health zones.

**Methods:** 16 focus group discussions and 40 semi-structured interviews were conducted with persons with epilepsy and their family, community leaders, community health workers, traditional healers, and health professionals in 2 health zones: Logo and Rethy.

**Results:** In the 2 zones epilepsy was a well-known disease and most people were aware of the possibility to treat this condition with anti-epileptic drugs. There was a request for a specialized center for epilepsy management. It was suggested to inform the population about epilepsy using communication channels of the church, traditional chiefs and health professionals. Reported challenges to obtain epilepsy treatment and care included: only access to traditional treatment, incurability of the epilepsy, stigma and taboo, lack of information and community support for people with epilepsy, unavailability of anti-epileptic drugs at primary health facilities, financial barrier to obtain anti-epileptic treatment (by patients and health professionals) and lack of training of health professionals to treat epilepsy. Traditional healers considered epilepsy contagious, transmitted by insects, saliva and by touching a person of the same sex during seizures. They said “during seizure a man should be assisted by woman, if another man does so, he will get epilepsy”.

**Conclusion:** Epilepsy is a well-known disease in Ituri and there is a great need and demand for a decentralized comprehensive epilepsy treatment program with affordable anti-epileptic drugs. Such a program need to include a community program that will address stigma and misconceptions.

### 32. KNOWLEDGE, ATTITUDE AND PERCEPTION ABOUT ONCHOCERCIASIS AND IVERMECTIN IN THE ONCHOCERCIASIS ENDEMIC HEALTH ZONE OF RETHY IN ITURI, DEMOCRATIC REPUBLIC OF THE CONGO (DRC)

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**Introduction:** Onchocerciasis is endemic in all provinces of the DRC and more than 26 million people are estimated to be at risk for onchocerciasis. Mass treatment with ivermectin was implemented in 2001. However, in Ituri in the Rethy health zone, due to insecurity, community distribution of treatment with ivermectin (CDTi) was only initiated in 2012. Optimal geographical and therapeutical coverage of CDTi is essential for the success of an onchocerciasis control program. To reach optimal efficacy it is important the community understands the benefit of the CDTi program and fully collaborates with it. In a recent case control study in Rethy investigating the link between epilepsy and onchocerciasis only 68.2% of eligible individuals reported to have taken ivermectin in 2014.

**Aim:** To understand the knowledge, attitude and perception of the community concerning onchocerciasis and the CDTi program.

**Methods:** 8 focus group discussions with community members and community directed distributors (CDDs) of ivermectin and semi-structured interviews with health professionals were conducted in the health zone of Rethy.

**Results:** Onchocerciasis is known as “filaria” in the health zone of Rethy. Ivermectin was well accepted as treatment against onchocerciasis and is also known as treatment for onchocerciasis, scabies, and lice and able to reduce itching, improve vision, improve sexual virility and fertility. During a first round of CDTi, side effects were a common reason for refusal to take ivermectin. Since the second round of CDTi the community understood the importance of taking ivermectin and considered side effects as a proof the drug was active against the parasites. However a local religious group discouraged people to take ivermectin (they said ivermectin is the drug of the second world “the world of Satan”). Moreover, CDDs complained about the lack of incentives for the distribution of ivermectin while for malaria control activities incentives were given.

**Conclusion:** In the Rethy health zone, ivermectin is a well-accepted treatment against onchocerciasis. To increase the success of the CDTi program health authorities should address the negative attitude of a religious group active in the area and also find ways to overcome the lack of motivation of the CDDs.

### 33. NODDING SYNDROME; CLINICAL MANIFESTATIONS, COMPLICATIONS AND TREATMENT

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**Introduction:** Nodding syndrome (NS) is a debilitating neurologic disorder affecting children and adolescents in East Africa. We are conducting a series of studies in the most affected districts of Uganda to determine aetiology, pathogenesis and treatments.

**Aim:** Determine the aetiology and pathogenesis, provide a comprehensive description of clinical features, comorbidities and complications, develop a staging system, supportive treatments and initiate studies of specific treatments.

**Methods:** First, we conducted a pilot study of 22 patients to describe the clinical features and determine patients' treatment needs and used this data to develop a supportive treatment program. Secondly, we conducted a detailed clinical, neurophysiologic and imaging study of 223 patients to describe the progressive development of symptoms, complications and comorbidities of NS. Third, based on preliminary aetiology studies, we are enrolling 230 patients in a phase II placebo-controlled trial of doxycycline as treatment.

**Results:** NS is a neurologic disorder with multisystem involvement. Complications of the untreated disease develop through five worsening clinical stages. Treatment with anticonvulsants and a program of physical, occupational, speech and language, psychological and nutritional rehabilitation therapy improves outcomes, function and wellbeing. The doxycycline trial is due to complete recruitment end of 2017.

**Conclusion:** The clinical manifestations and function of patients with NS improve with symptomatic treatments. A definitive cure and preventive intervention is awaited.

### 34. NODDING SYNDROME: ETIOLOGY REMAINS UNKNOWN

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**Introduction:** Nodding Syndrome (NS) is a pediatric epileptic encephalopathy first described in Tanzania, with recent epidemics in South(ern) Sudan (SS) and Uganda (UG: 2000-2013). NS epidemics coincided with civil conflicts in which populations were moved to crowded internal displacement (IDP) camps where infectious disease was rife and food quality poor. International conferences in Kampala (2012) and Gulu (2015) examined NS epidemiology, etiology, classification, clinical features and treatment.

**Aim:** Examine role of infection in NS.

**Methods:** Analyze relevant studies.

**Results:** A 2001 WHO-led study of NS in SS revealed widespread nematode infection, with significant NS case association of both *Onchocerca volvulus* (OV, OR 9.22,  $p=0.0003$ ) and *Mansonella perstans* (OR 3.22,  $p=0.005$ ). Later CDC-led studies in SS-UG confirmed the association between NS, OV, and *Mansonella* sp., but subsequent work has been limited to OV [1]. A recent NIH-led study [2] proposes that NS is an autoimmune-mediated disease triggered by OV antigens. They found autoantibodies to leiomodulin-1 (an actin-binding protein) in serum of OV-infected NS patients (54.5%) and OV-infected controls (41.4%), thought to be “pre-NS”. Another recent study [3] reported NS case association with prior measles infection and pointed to time-course and clinical similarities between NS and the post-viral disorder subacute sclerosing panencephalitis (SSPE). Preliminary CDC observations of intranuclear crystalline structures and neurofibrillary tangles in the brains of 3 Ugandan NS patients is consistent with SSPE but not with an autoimmune CNS disorder.

**Conclusion:** While the cause of NS remains unknown, its acquisition in IDP camps is probable. Malnutrition and infections, notably measles, cause immunosuppression which invite parasites, including opportunistic nematodes. OV is an unlikely cause of NS because they differ markedly in geospatial distribution. Non-neural tissues rich in LMOD-1 are spared in NS, and increased LMOD-1 in NS could result from release of muscle protein during seizure activity.

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