

**Second international workshop on  
onchocerciasis-associated epilepsy  
19-21 September, University of Antwerp,  
Belgium**

# What has been achieved?

- OAE is a preventable condition
- OAE is treatable
- OAE prevention and treatment are at low cost
- Interventions can be extremely cost beneficial
- Easy to reduce incidence and mortality
- Community based interventions work for prevention and care
- Slash & Clear very effective in certain areas

# What has been achieved?

- Increasing intention of the “onchocerciasis community” and “brain community” for the need to work together
- Pathogenesis: new insights thanks to better knowledge of the biology of the worm
- Detection of viruses in nematodes opens a new field of research
- New promising anti-filarial drugs are being tested
- New rapid test are being evaluated

# What has been achieved?

- OTS recognised OAE
- Interest to revisit onchocerciasis disease burden
- Establishment of Brain health unit
- Increasing intention of the “onchocerciasis community” and “brain community” for working together
- Pathogenesis: new insights thanks to better knowledge of the biology of the worm
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# Main conclusions

- OAE exists
- OAE is an important public health problem
- Very high burden of disease in certain villages

## Need

- OAE policy and interventions
- Advocacy, funding

# Recommendations

# Onchocerciasis elimination programme

- Do not forget in many onchocerciasis endemic areas onchocerciasis has not been eliminated as a public health problem
- Revisit the burden of disease caused by river blindness compare this with burden of disease caused by river epilepsy
- Prioritise strengthening onchocerciasis elimination efforts in areas with a high disease prevalence (much more cost beneficial for communities)
- Involve affected communities in elimination strategies

# Onchocerciasis elimination programme

- High ivermectin coverage of children 5-15 years is important
- Consider extra ivermectin distribution in schools if 6 monthly CDTI is not possible (together with praziquantel in schistosomiasis areas)
- Increase coverage of pregnant women by offering ivermectin post-CDTI to lactating women at child vaccination sites
- Use CDDs to recognise suspected cases of epilepsy (5 questions)
- In areas with high epilepsy prevalence CDTI coverage should be critically reviewed
- Collaborate with *T solium* (neurocysticercosis programme)



# Onchocerciasis elimination programme

- Need a simple OAE definition for epidemiological studies to estimate the burden of disease and for programmatic decisions to identify areas that may need additional support/interventions
- For pathogenesis studies a more specific OAE definition is needed: use additional test or a very characteristic clinical presentation: nodding syndrome
- We can not wait for developing OAE policies until we have a identified biomarker to confirm OAE
- Compare with long COVID: A post-COVID syndrome definition was proposed by WHO as a starting point to investigate this phenomenon

# Onchocerciasis elimination programme

- Increase OAE awareness in communities
- OAE awareness need to be included in CDTI mobilisation campaigns
- Communities need to know why it is important to take ivermectin
- Communities should be asking for the drug and ivermectin should remain available for those who missed to take it during CDTI
- WHO should update his website on onchocerciasis and include OAE information

# Brain health programme

- Recognise OAE exist by expert committee (compare with OTS)
- Contact person within the Brain health unit for OAE
- Assist in creating awareness about OAE
- This will decrease epilepsy related stigma
- Help the “OAE community” to speak at neuro conferences
- Take into account epilepsy prevalence data in the distribution of anti-seizure medication (OAE areas need more drugs, not necessary other ones)

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# Brain health programme

- Try to bring pharmaceutical industry on board
- Clinical trials or at least good cohort studies are needed to evaluate the effect of anti-seizure medication in Africa
- Place of levetiracetam?
- Organise an epilepsy workshop in a highly affected area
- Focus also on the Democratic Republic of Congo (DRC) because most OAE is in the DRC

# Brain health programme

- An efficient supply-line of anti-seizure medication is extremely difficult to organise in onchocerciasis areas (very remote and security problems). Therefore collaborate with HIV and Mectizan donation programme?
- Work new epilepsy treatment target (in analogy with the HIV 90 90 90 target)
  - 80% treated
  - 80% adherent to treatment
  - 80% seizure free

# For everybody

Increase collaboration

Increase communication

Exchange samples

Open source publishing and data sharing

Advocacy (example HIV)

More ambitious targets