



## **I Am Breathing**

### **Additional resources**

Compiled by the GHF Classics volunteer team

#### **News Articles:**

[Simple blood test could one day diagnose motor neuron disease](#) (Science Daily, 2020)

Outlines the need to improve ALS diagnosis in the future and describes potentially successful research from the University of Sussex on a biomarker to be used for that sake

[New Clues To ALS And Alzheimer's Disease From Physics](#) (NPR, 2020)

Names a mutation disrupting phase transition inside cells as a potential source of ALS, Alzheimers, and other degenerative diseases

[From Oregon to Belgium to Victoria – the different ways suffering patients are allowed to die](#) (The Conversation, 2017)

Compares different jurisdictions in their laws on euthanasia/assisted dying and provides some statistics on the use of these opportunities

[“It’s a White Disease!”](#) (Anthropology News, 2019)

Describes the dual misconception that ALS only affects white people but is simultaneously not impacted by race and the dangers of misdiagnosis this brings

Links between the 2014 ALS ice bucket challenge and the 2014 movement against police brutality against Black people in the US

[The Ice Bucket Challenge and the promise — and the pitfalls — of viral charity](#) (Vox, 2019)

Checks in with the ALS Association five years after the ALS Ice Bucket Challenge to outline its effects on practical work

Outlines the dangers of such trends in non-profit work, but also how the ALS Association did comparably well and managed to avoid most of these dangers

#### **Scientific Publications:**

[Amyotrophic lateral sclerosis and motor neuron syndromes in Asia](#) (J Neurol Neurosurg Psychiatry 2016)

Outlines epidemiological findings (s.a. Prevalence, age of onset, prognosis) and genetic findings on ALS & MND in Asian cohorts and compares those with Western findings

**[Motor Neuron Diseases in Sub-Saharan Africa: The Need for More Population-Based Studies](#)** (Hindawi, 2015)

Review summarizing epidemiological and genetic findings on MND in Sub-Saharan Africa, concluding differences to European and North-American Research  
Highlights the need for more neurological research being conducted in African countries, summarizes existing barriers and progress made, and suggests potential solutions

**[Unstable terminality: negotiating the meaning of chronicity and terminality in motor neurone disease](#)** (Sociology of Health and Illness, 2015)

Sociological analysis describing how MND does not fall into the chronic nor the terminal illness category and thus needs its own category of “unstable terminality”

Points out some of the resulting problems for patients, carers and the healthcare system based on qualitative evidence from Norway and illustrates how these might be further exacerbated and extended into other diseases through medical progress

**Other:**

**[IAmBreathing.com](#)**

Website of the film containing further information on Neil’s disease as well as his blog with annotations from Louise

**[Breathing Platitudes](#)**

Louise Oswald’s memoir, published July 2020

**[Motor Neurone Disease Association](#)**

National Charity in England, Wales and Northern Ireland focused on improving access to care, research and campaigning for people living with or affected by MND