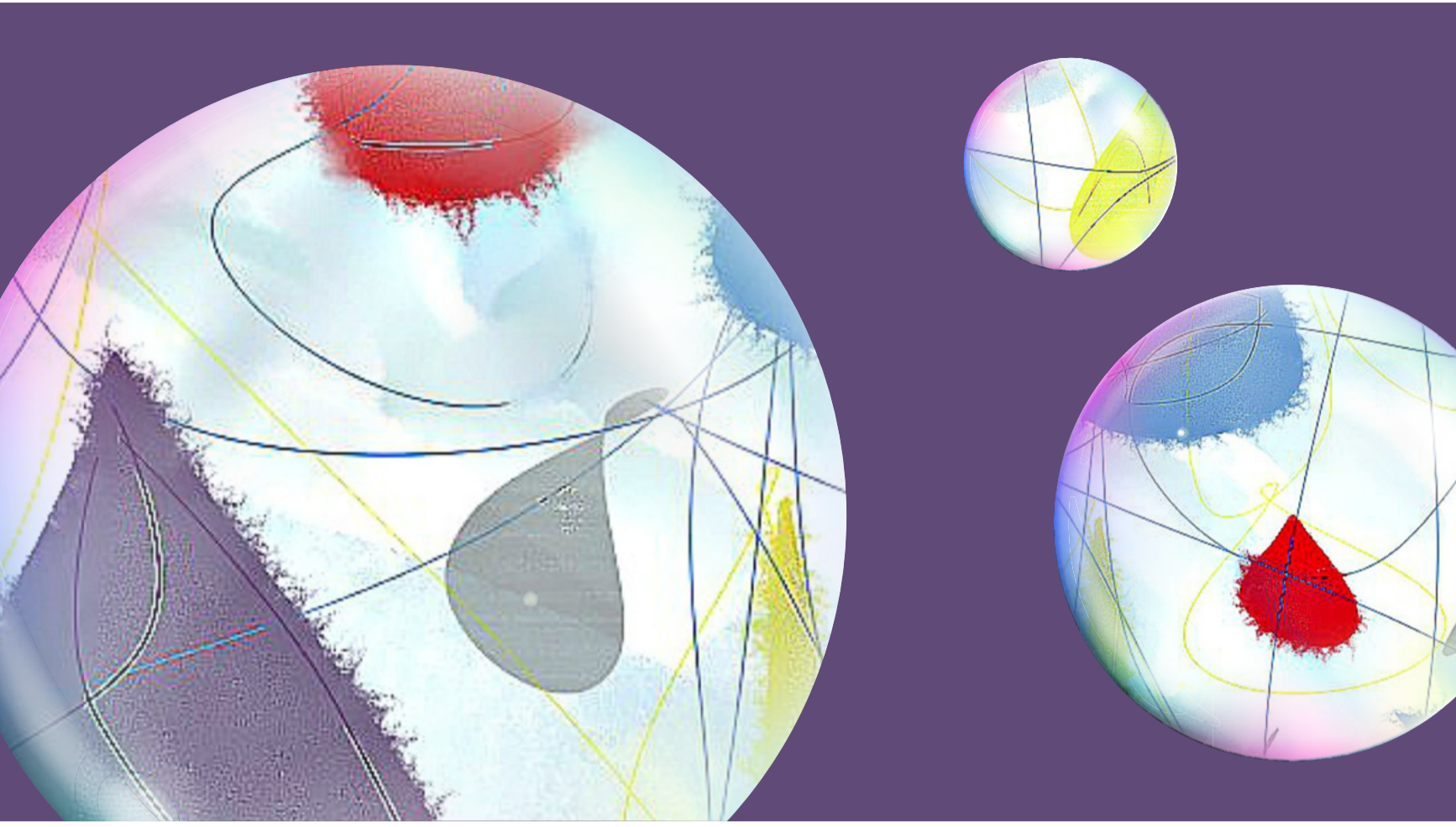


# Ethical considerations in genetic testing in ALS



Adapted from: "Teardrops" 2012. Sarah Ezekiel. All rights reserved.

Wednesday 8 December 2021 | 15:25–16:10  
Greenwich Mean Time

Register for MND

In conversation

Ammar Al-Chalabi and  
Nita A. Farahany



**Ammar Al-Chalabi, MB, ChB, PhD**

Professor of Neurology and Complex Disease  
Genetics, King's College London, London, UK

Professor Al-Chalabi is one of the most recognizable and  
charismatic researchers in motor neuron disease (MND).  
Stressing the importance of international collaboration,  
Professor Al-Chalabi leads one of the world's top research  
hubs for MND. He and his team are working on finding the  
causes of amyotrophic lateral sclerosis (ALS), and what might  
influence the way the disease manifests and progresses.

He co-leads Project MinE, a whole-genome sequencing  
project aiming for 15,000 participants with ALS; leads the  
European JPND STRENGTH consortium, looking at the  
development of personalized treatments, and co-leads the  
national ALS register of England, Wales and Northern Ireland.  
While Professor Al-Chalabi's research leans towards complex  
genetics, much of his work is driven by questions and  
concerns voiced by his own patients.

In 2016 he received the Sheila Essey Award from the American  
Academy of Neurology and ALS Association and in 2020  
he received the Forbes Norris Award from the International  
Alliance of ALS/MND Associations and was a cowinner of the  
Healey Center International Prize for Innovation in ALS.



**Nita A. Farahany, JD, MA, PhD**

Professor of Law and Philosophy,  
Duke University, Durham, NC, US

Professor Nita Farahany is a leading scholar on the ethical,  
legal, and social implications of emerging technologies in  
biosciences, particularly genomics and neuroscience. She is  
the Robinson O. Everett Distinguished Professor of Law and  
Philosophy at Duke University, the Founding Director of the  
Duke initiative for Science and Society, and the Chair of the  
Duke MA program in Bioethics and Science Policy.

Professor Farahany is an appointed member of the National  
Advisory Council for the National Institute of Neurological  
Disease and Stroke, an elected member of the American Law  
Institute, member of the Neuroethics Working Group of the  
US Brain Initiative, the Global Precision Medicine Council for  
the World Economic Forum, and the New York Bar. In 2010  
she was appointed by President Obama to the Presidential  
Commission for the Study of Bioethical Issues, where she  
served until 2017. In 2020, she earned the lifetime distinction  
of becoming a Fellow of the American Association for the  
Advancement of Science for "distinguished contributions to  
the field of neuroethics, enabling responsible and equitable  
development and implementation of new knowledge and  
technologies in neuroscience."

Professor Farahany is a frequent commentator for national  
US media and radio shows and has spoken at major events  
including the Aspen Ideas Festival, TED, the World Economic  
Forum, and judicial conferences.

## About the Artist

**Sarah Ezekiel** is one of the world's leading eyegaze artists;  
she has exhibited all over the UK, including the Royal Academy  
Schools in London, and also at the Katara Art Centre in Doha.

**"Teardrops was created after I fell out of bed one morning.  
My carer couldn't hear me calling for help and I was lying  
on the floor for an hour. Feeling bruised and sore, I started  
to paint and decided that I could create something good  
from a bad experience. The colours represent my optimism  
despite having MND."**



Sarah studied art and history of art, but when, at the age of 34, she was  
diagnosed with motor neuron disease (MND), she believed that she  
would never create anything again. In fact, she continues to work using  
assistive devices, offering inspiration, support and a positive outlook to  
families in a similar situation.