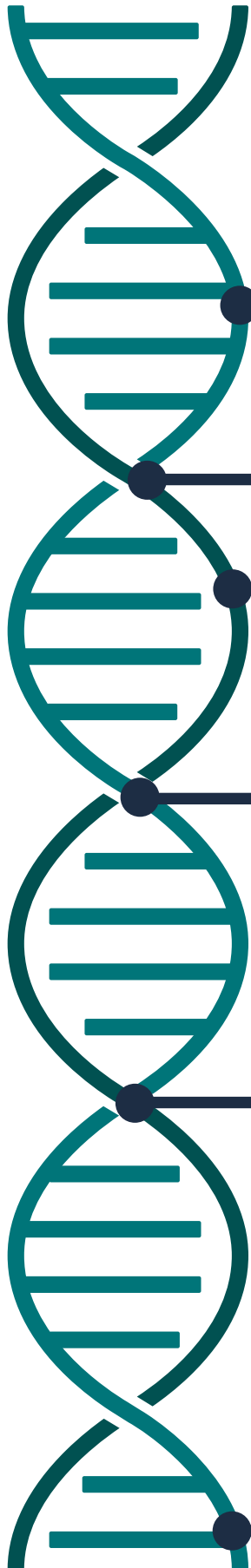


The Alliance and Genetics



The Alliance is a global network of ALS/MND associations that was formed in 1992. The objectives of the charity were, and still are:

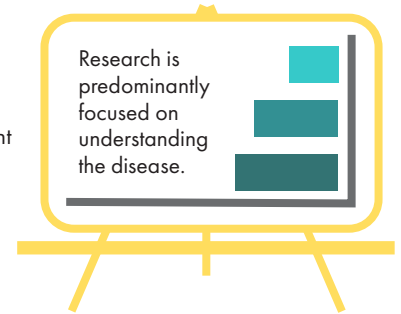
- (a) the relief of persons worldwide who are, or who are suspected of being affected by Amyotrophic Lateral Sclerosis ("ALS") Motor Neurone Disease ("MND") and associated conditions, and
- (b) the advancement of the education of the public on matters relating to ALS/MND.

The Alliance's strategies are informed by people living with ALS/MND (PALS) and their Caregivers (CALs), we help our members thrive by adding value to existing and future associations through curation and creation of information and by acting as a global gateway through which Alliance Members, PALS and CALs, internal, and external stakeholders connect.

DEC
2019

THE ALLIANCE RESEARCH LANDSCAPE RESULTS

Genetics represents only **10%**, but can provide significant contributions to our understanding of ALS/MND.



MAR
2021

THE ALLIANCE GENETICS ROUNDTABLE

OUTCOMES:

- Add genetic counseling and testing to Fundamental Rights of People Living with ALS/MND
- Develop education and resource materials on ALS/MND genetics
- Facilitate data collection
- Develop clinical guidelines

JUN
2021

THE ALLIANCE INNOVATION ROUNDTABLE

One of the projects considered is an open data project aimed at reducing duplication of efforts, and breaking down data silos.

SEP
2021

INTERNATIONAL CONSORTIUM FOR GENETIC TESTING INDUSTRY ROUNDTABLE

Precision medicine in ALS/MND will require identifying mutation "hot spots" that vary regionally, and better investment in natural history data.

DEC
2021

DR. JEANNINE HECKMANN

Presents new data indicating genetic cause of disease in **>11%** of ALS/MND patients with African genetic ancestry.

DR. CHELSEY CARTER

Presents her research on biological racism in ALS/MND, furthering the notion that there is lack of ethnically diverse representation in both clinical care and research in ALS.

MND CONNECT

Dr. Orla Hardiman states that the ALS/MND community needs to expand research initiatives globally in order to make progress in understanding –

WFN SYMPOSIUM

Dr. Adriano Chio and Kristiana Salmon indicate that improving genetic understanding, and access to genetic testing, will require ensuring the conversation extends beyond the vestablished consortia and research initiatives, and engages remote and under-represented regions.

"We make more progress by working together."



JUN
2022

THE ALLIANCE GENETICS SUMMIT



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS