



## **CASK Coalition Rules**

The CASK Coalition consists of the following Founding Members:

Angelina Cask Neurological Research Foundation Ltd (Australia);

Angelina Cask Neurological Research Foundation Inc (USA)

Cask Research Foundation UK

AND

Association Enfants CASK France

(collectively referred to as '**the Founding Members**')

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1. Any new member wishing to join the CASK Coalition must adhere to the following Rules to be considered and accepted to join the CASK Coalition:
    - (i) The New Member must be a registered Charity pursuant to their home country requirements and must provide evidence of being a Registered Charity.
    - (ii) The New Member must maintain their charity registration and notify the CASK Coalition should this registration be changed in any way.
    - (iii) The primary mission of the New Member must be to advancing scientific research related to treatment of CASK Gene disorders and associated conditions.
    - (iv) The New Members' mission, objectives and values must align with those of the CASK Coalition.

- (v) The New Member must provide a copy of its mission, objectives and values to the CASK Coalition.
- (vi) The New Member must support the CASK Coalition mission, objective and values.
- (vii) The New Member must actively support the CURE CASK Campaign and any other joint initiatives launched by the CASK Coalition at the time of joining.
- (viii) The New Member must adopt, follow and actively support the Global CASK Road Map.
- (ix) The New Member must actively liaise with stake holder support (including but not limited to the community, researchers, grant providers, public and private sectors) in accordance with the Global CASK Coalition Road Map.
- (x) The New Member must support RARE -X DCP and not create their own directly competing data collection program. This excludes national registries collecting patient demographic data and contact details.
- (xi) The New Member understands that there will be a probationary period of six (6) months. Upon successful completion of the probationary period the organisation will offered full membership status, wherein they may use the CASK Coalition logo, be able to participate in the annual fundraiser and be part of the annual Roadmap review.
- (xii) The New Member must adhere to the Member Participation Guidelines.

January 2024