ADDOR FOUNDATION CONSTITUTION







Anne Dyer

Daniel O'Reilly

Anne Dyer & Daniel O'Reilly Foundation

Anne Dyer was 46 years old when she died of Huntington's disease (HD).

Daniel O'Reilly, Anne's son has inherited this fatal disease



There is no cure for Huntington's disease and its progress cannot be reversed or slowed down.

But with your help, HD can be defeated

ADDOR Foundation

Constitution

1. Name

The charity's name is ADDOR (Anne Dyer & Daniel O'Reilly Foundation)

2. Objective

The objective of ADDOR is in providing public benefit for sufferers and their families, of all age groups, in any part of the world, who have inherited and are living with the incurable illness Huntington's disease (HD).

3. Charitable Purposes

ADDOR will look to achieve its objective by providing funding worldwide, with the aim of advancing the health and towards the goal of saving lives, as well as providing financial support to sufferers of Huntington's disease (HD) and their families, by:

- 3.1 Financial support for those research projects seeking to find:
 - A cure to eradicate HD
 - Treatments to slow or mask the onset of HD
 - Medicines that help in alleviating and control of the pain and suffering of patients with the terminal illness Huntington's disease (HD).
 - Treatments to reverse an existing HD sufferer's condition.
- 3.2 Financial aid to sufferers of HD, which would benefit their quality and dignity of life whilst living at home or in a care facility.
- 3.3 Funds to purchase equipment, which would benefit HD sufferers and their families, particularly those with a limited income and in financial hardship. A chair suitable for an HD sufferer, currently costs in excess of £2000.
- 3.4 Regular funding to supplement grants from government and other agencies, to ensure HD suffers have the opportunity to be placed in the most suitable care homes, which may otherwise be denied them, due to financial constraints, thus giving them the best possible conditions, care and treatment in their final moments before death.
- 3.5 Funding for younger (juvenile) HD sufferers, to give them the opportunity to achieve goals or dream's, they may aspire to meet, within their shortened life expectancy. In particular benefiting those families of young sufferers, to whom achievement of their child would result in financial hardship.
- 3.6 Funding to ensure that families of HD sufferers have the financial support to able to be with their family member, as much as possible, if they are in a care facility, but who may be limited from doing so, by financial constraints. For example helping with travel costs.

3.7 Finally in addition to ADDOR's fund raising activities, ADDOR will also undertake to promote increased worldwide awareness of HD, this inherited, cruel, destructive and incurable disease. Seeking with that greater awareness, comes the opportunity to increase funding not only for this charity, but also to support other debilitating motor neuron diseases charities.

4. Aim

The aim with this charity is to ensure that nearly 100% of donations go towards research projects and in aid to Huntington's disease (HD) sufferers and their families.

The individuals (Trustees) running this charity are volunteers. There will be no money taken for salaries or individual expenses.

Auditing of the accounts, will be undertaken by a no fee Accountant.

Any monies paid to ADDOR will go directly to a bank account opened in the name of the foundation. Money will be used for such things as postal costs, setting up a website, with every effort made to minimise these costs.

5. Trustees

The charity shall initially be managed by a committee of the following three trustees:

Thomas Francis O'Reilly

Timothy Nigel O'Reilly

Andrew Kevin O'Reilly

The number of Trustees may be increased by agreement of the above three Trustees.

6. Carrying out the purposes

In order to carry out the charitable purposes, the trustees have the power to:

- 5.1 Raise funds, receive grants and donations
- 5.2 Apply funds to carry out the work of the charity
- 5.3 Co-operate with and support other charities with similar purposes
- 5.4 Do anything which is lawful and necessary to achieve the purposes
- 5.5 Make the decision on which areas of research and which individual sufferers will be supported, taking into account when appropriate, the recommendations of the Technical Support Advisor.

6 Membership

The charity will not initially be open to membership, but this will be reviewed annually by the Trustees and should circumstances be such as membership deemed necessary, then the rules of this charity will be rewritten to incorporate membership.

7 Annual General Meeting - AGM

- 7.1 An AGM must be held every year, with 14 days prior notice given to the three Trustees advising them what is on the agenda. Minutes must be kept of the AGM. These meetings will be held by video conference link.
- 7.2 There must be at least two Trustee present at the AGM.
- 7.3 Each Trustee has one vote
- 7.4 The Trustees shall present the annual report and accounts

8 Trustees Meetings

- 8.1 Trustees must hold at least 2 video conference meetings each year. Initially the role of chair, treasurer and secretary will be handled by one of the Trustees. This may change in the future dependant on how the Foundation develops. Trustees may act by majority decision.
- 8.2 At least 2 trustees must be present at the meeting to be able to take decisions. Minutes shall be kept for every meeting.
- 8.3 If trustees have a conflict of interest they must declare it and leave the meeting while this matter is being discussed or decided.
- 8.4 During the year, the trustees may appoint additional trustees, as deemed necessary by the existing three Trustees.
- 8.5 The trustees may make reasonable additional rules to help run the charity. These rules must not conflict with this constitution or the law.

9 Money and Property

- 9.1 Money and property must only be used for the charity's purposes.
- 9.2 Trustees must keep accounts. The most recent annual accounts to be made available and can be seen by anybody on request.
- 9.3 Trustees cannot personally receive any money or property from the charity,
- 9.4 Money must be held in the charity's bank account. All cheques issued must be signed by the Named Trustee, initially Thomas Francis O'Reilly. All BACS payments must be authorised by the Named Trustee, initially Thomas Francis O'Reilly.

10 Privacy and Data Protection

The Privacy and Data Protection Policy and Guidelines are set out in a separate document, ADDOR Foundation Privacy and Data Protection Statement. A copy of the document is are available on the ADDOR website.

11 General Meetings

If the Trustees consider it is necessary to change the constitution, or wind up the charity, they must call a General Meeting so that the Trustees can make the decision. Minutes must be kept.

- 11.1 Winding up any money or property remaining after payment of debts must be given to a charity with similar purposes to this one.
- 11.2 Changes to the Constitution can be made at AGMs or General Meetings. No change can be made that would make the organisation no longer a charity.
- 11.3 General Meeting called on request by one of the Trustees.

12 Technical Support

Technical input to ADDOR regarding research organisations and developments will be provided by:

Daniel Timothy O'Reilly: McGill University, Montreal, Canada.

13 Setting up the Charity

This revised constitution was adopted on 11th April 2018 by the people whose signatures appear below. They will be the trustees until further notice is given of changes to the number of Trustees or the names of the Trustees

Signature of Trustee Printed Name and Address of Trustee

Thomas Francis O'Reilly

Flat 19

2-5 Royal Crescent

Weston Super Mare

Somerset. BS23 2AX

Milly

Timothy Nigel O'Reilly

38 Downview Road

Barnham, Bognor Regis

West Sussex. PO22 0EF



Andrew Kevin O'Reilly

The Cedars

Sterridge Valley

Berrynarbor

Ilfracombe

Devon. EX34 9TB

