

ADDOR Foundation

Privacy and Data Protection Statement

The ADDOR Foundation is committed to protecting your privacy. This policy explains how we collect and use the personal information you provide to us whether online or via phone, mobile, e-mail, letter or other correspondence.

By using our website, any of our services, or providing us with any personal information we will assume you are agreeing to your information being used and disclosed in the ways described in this policy.

1. Who we are?

The ADDOR Foundation raises money to support research projects in pioneering new treatments and cures for Huntington's disease (HD). The Foundation also supports helping HD sufferers and their family's members financially, particularly those with limited incomes; young HD sufferers achieve their goals in life and very importantly to promote extensive worldwide exposure of this cruel incurable disease.

The ADDOR Foundation is not yet registered as a charity in England and Wales, with the Charity Commission (CC). As a new charity ADDOR does not have sufficient annual income to be eligible for registration. In due course should annual funding be above that required by CC then ADDOR will seek registration.

ADDOR is however seeking to be listed on the Funding Register (FR), when that is approved the registration number will be added to all ADDOR documents and its website.

Application is also being made to HMRC to recognise ADDOR as a charity and make it eligible for Gift AID status.

2. Data Protection Regulations

In carrying out our day to day activities ADDOR process and store personal information relating to our supporters and we are therefore required to adhere to the requirements of the General Data Protection Regulation that comes into force 25th May 2018. We take our responsibilities under this regulation very seriously and we ensure the personal information we obtain is held, used, transferred and otherwise processed in accordance with that Regulation and all other applicable data protection laws and regulations including, but not limited to, the Privacy and Electronic Communication Regulations.

3. What personal information do we collect?

Personal information is information that can be used to identify you. It can include your name, date of birth, email address, postal address, telephone number, mobile telephone number, fax number, bank account details, credit/debit card details and whether you are a UK tax payer so that we can claim Gift Aid (please rest assured we do not collect information about your actual tax payments, just whether you are a tax payer). We collect personal

information about you when you ask about our activities, register with us (for example, registering on a discussion board or for a publication), make a donation to us, register for an event, engage with our social media or message boards, order products and services (such as publications and email newsletters), or otherwise give us personal information.

If you do nothing other than read pages or download information from our website, we may gather information about this use, such as which pages are most visited and which events or activities are of most interest. This information can be used to help us improve our website and services, ensuring we provide you with the best service. Wherever possible, the information we use for this purpose will be aggregated or anonymised i.e. it will not identify you as an individual visitor to our website. More information can be found in the section below entitled “Our website”.

We will not collect “sensitive personal information” about you.

4. Credit, Debit card, Banking, Cash payment information

Donations to ADDOR can be made either by payments using the Banking BACS system or using Pay Pal or cash. ADDOR banks with Lloyds, any information contained in the banking statements of ADDOR, is only seen by the Bank, the Trustees and the appropriate authorities such as HMRC, this information will not be available to any other sources.

Payments made through Pay Pal often using Credit or Debit cards, will be seen as money transfers to the ADDOR bank account. There will be no records transferred from Pay Pal, such as credit and debit card details. ADDOR Trustees will be able to access the ADDOR Pay Pal account and see donations made and who they came from. None of this information will be disclosed by the ADDOR Trustees. All information held by Pay Pal will be in accordance with their guiding principles on Data Privacy.

Should there be donations received by cheque or cash, then this will require us to hold certain information in order to provide transparency on those payments to ADDOR. This information will be stored and not disclosed to anyone or any other organisation outside of the ADDOR Trustees. They will be responsible for conforming to ADDOR Data Privacy Guidelines and in keeping with the laws on Data Privacy.

5. Why do we collect and how do we use your information?

Whilst it is not ADDORs aim to collect data, we may collect your personal information for a number of reasons, such as:

- to provide you with the services, products or information you have requested;
- to process any donation(s) we may receive from you;
- to ask you to help us raise money or donate money to our charity, but always in accordance with our supporter promise;
- to provide you with information about our work or our activities, that you have asked to receive;
- for administration purposes e.g. we may contact you about a donation you have made or event you have expressed an interest in or registered for;
- for internal record keeping, such as the management of feedback or complaints;
- to analyse and improve the services we offer;
- the use of IP addresses to block disruptive use, to record website traffic or to personalise the

way our information is presented to you to identify your approximate location;

- where it is required or authorised by law; and
- assessing your personal information for the purposes of credit risk reduction or fraud prevention (regrettably some people target charities for illegal purposes such as money laundering and, quite rightly, we are required to monitor financial activity and report suspected fraud to the appropriate authorities).

ADDOR may supplement or add to the information held about you with information that is available through, or received from, other sources e.g. public registers, media sources including the internet. This allows us to send you the most relevant information and promote fundraising opportunities. We may contact you for marketing purposes by mail, e-mail, mobile telephone, text or social messaging; in some cases, this will require getting your permission. We may also send you service communications via e-mail, text or social posting.

To comply with our obligations as a charity, we must take reasonable and appropriate steps to know who our donors are, particularly where significant sums are being donated. This means that we may conduct research, including accessing information which is already publicly available, on prospective donors, partners or volunteers to ensure it would be right for us to accept support whether that is from an individual or organisation. This will help to give assurance that the donation is not from an inappropriate source and to safeguard our reputation. This does not mean that we will question every donation, nor that we will research lots of personal and other details about every donor. Any information we do collect for this purpose will only consist of what is necessary for us to meet these requirements and will be processed in line with your rights.

It is your choice on the type of communications and information you receive about our charity and the ways in which you can get involved. You can change your mind at any time by contacting Thomas O'Reilly Trustee, ADDOR Foundation, Flat 19, 2-5 Royal Crescent, Weston Super Mare, Somerset, BS23 2AX United Kingdom 1LE or by telephone 0737 834 606 or via e-mail: info@addor.co.uk.

We will not use your information for marketing purposes if you have asked us not to. However, we will retain your details on a suppression list to help ensure we do not continue to contact you.

6. Information sharing and disclosure

We will not sell or swap or share your information with any third party.

We may however disclose your personal information to third parties if we are required to do so through a legal obligation (for example to the police or a government body); to enable us to enforce or apply our terms and conditions or rights under an agreement; or to protect us, for example, in the case of suspected fraud or defamation.

We do not and will not share your information for any other purposes.

7. The accuracy of your information

We aim to ensure that all information we hold about you is accurate and, where necessary, kept up to date. If any of the information we hold about you is inaccurate and either you advise us or we become otherwise aware, we will ensure it is amended and updated as soon as possible.

8. Under 16s

If you are aged 16 or under, and would like to participate in a fund raising event, make a donation with us, please make sure that you have your parent/guardian's permission before giving us your personal information. When we collect information about a child or young person, we will make it clear as to the reasons for collecting this information and how it will be used.

9. Vulnerable circumstances policy

We recognise the importance of protecting our vulnerable supporters and follow the guidance issued by the Institute of Fundraising on treating donors fairly. We believe this helps to support the Trustees and any fundraisers who come into contact with supporters in providing high quality customer care, ensuring anyone donating to the charity is in a position to make a free and informed decision.

10. Storing your information

It is envisaged that the information we store and process stays within the UK.

We will keep your information for as long as required to enable us to operate our services but we will not keep your information for any longer than is necessary. We will take into consideration our legal obligations and tax and accounting rules when determining how long we should retain your information. When we no longer need to retain your information we will ensure it is securely disposed of, at the appropriate time.

11. Our website

Our websites use cookies to help them work well and to track information about how people are using them. More information on cookies can be found below.

For all areas of our website which collect personal information, we use a secure server provided by a website hosting service. Although we cannot 100 per cent guarantee the security of any information you transmit to us, we enforce strict procedures and security features to protect your information and prevent unauthorised access.

Our website contains links to other websites belonging to third parties and we sometimes choose to participate in social networking sites including but not limited to YouTube and Facebook. We may also include content from sites such as these on our website however, would advise that we do not have any control over the privacy practices of these other sites. You should make sure when you leave our site that you have read and understood that site's privacy policy in addition to our own.

12. Cookies and spotlight tags

ADDOR Foundation uses “cookies” and “spotlight tags” to help track the success of our online advertising and monitor the usage of our website. We use Google Analytics for our web analytics and work with DoubleClick to monitor our online advertising results.

With both cookies and spotlight tags, the information we collect and share is anonymous and does not personally identify you. It does not contain your name, address, telephone number, or email address.

What is a cookie? A cookie is a small file of letters and numbers that we may put on your computer or mobile device when you access our website. These cookies allow us to distinguish you from other users of the website helping us to provide you with a good experience when you browse our website and also allow us to improve our site. For example, they will tell us whether you have visited our site before or whether you are a new visitor.

[Access the “All About” Cookies website](#) - to find out more about cookies and how you can disable.

What are spotlight tags?

There is no online advertising on ADDOR’s website. Should this policy change and online advertising be added, then spotlight tag records access to a website, as part of online advertising. Spotlight tags allow a company to track, measure and report on activities that happen on a website after you see or click on an ad. These tags allow measurement of the effectiveness of online marketing campaigns.

In the event this policy does change, notification of the change will be advised on the website.

13. Changes to the policy

This policy is correct as of March 2018. We will regularly review and update this Privacy and Data Protection Statement and will update, modify, add or remove sections at our discretion. Any changes will be notified to you either via e-mail or through an announcement on our website and your continued use of our website, any of our services and/or the continued provision of personal information, after we have posted the changes to these terms, will be taken to mean you are in agreement with those changes.

14. Your rights

You have the right to:

- request a copy of the information we hold about you;
- update or amend the information we hold about you if it is wrong;
- change your communication preferences at any time;

- ask us to remove your personal information from our records;
- object to the processing of your information for marketing purposes; or
- raise a concern or complaint about the way in which your information is being used.

If you wish to find out more about these rights, or obtain a copy of the information we hold about you, please contact Thomas O'Reilly, Trustee:

ADDOR Foundation
Flat 19
2-5 Royal Crescent
Weston Super Mare
Somerset
BS23 2AX
United Kingdom
Tel: 0737 8346 606
Email: info@addor.co.uk

15. Privacy queries

If you have any questions or queries about this Privacy and Data Protection Statement, please contact our Thomas O'Reilly using the above address and contact details.