Volunteer privacy statement

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Volunteer privacy statement

Introduction

The Huntington’s Disease Association takes the privacy of our volunteers very seriously. We are committed to protecting and keeping any personal data you share with us, or we get from other organisations, safe.

The Huntington’s Disease Association is subject to the UK General Data Protection Regulation and the Data Protection Act 2018. We are registered with the Information Commissioners Office as a Data Controller (registration number: ZA233740).

This volunteer privacy statement explains what personal information we will hold about you, how we collect it, how we will store it and how we will use it. We will not share your personal information with third parties and other organisations unless you give us prior agreement to do so. Most importantly, this statement will make clear to you your rights regarding the use of your personal information and what to do if you no longer wish to volunteer or be contacted by the Huntington's Disease Association.

Please ensure that you read this privacy notice and any other similar notice we may provide to you and contact us if you have any questions about the data we collect and hold about you on info@hda.org.uk or 0151 331 5444.

Data protection principles

The Huntington’s Disease Association complies fully with the data protection principles when gathering and using personal information, these principles are set out within our Data Protection Policy.

Legal basis for using your information

In accordance with the UK General Data Protection Regulation, the lawful reason we use to process your information if you volunteer for the Huntington’s Disease Association is ‘legitimate interest.’

Legitimate interest

We process your personal information because there is a legitimate interest for both the Huntington’s Disease Association and you to fulfil your volunteer role.

Contract

For some volunteer roles, such as membership of HD Voice, the charity’s Patient and Public Involvement group, we process your information because there is a contract in place between you and the Huntington’s Disease Association in relation to your role.

How we collect information

We will only collect information from you that is necessary for your volunteer role and for future monitoring and evaluation purposes. Where information is stored for monitoring and evaluation purposes we will ensure that it is anonymised at the earliest possible stage in accordance with our data protection policies.

If in the future, we would like to use your information for another purpose, or the reason for using your personal information has changed we will ask your permission before doing so.

Directly from you

We obtain personal information when you give it to us directly, during the recruitment and selection process and during the time you volunteer at the Huntington’s Disease Association.

Other organisations and third parties

We may obtain information about your from third party organisations such as Disclosure and Barring Service or from people you name as referees for your volunteer role.

What information do we collect and hold

The personal information we collect and how we will use it is dependent on your volunteer role and the reason you gave us the information to begin with. We may collect the following information to identify you on our systems, record your volunteer interests and responsibilities and to contact you about volunteer opportunities and key charity updates that are relevant to your role.

- Name
- Date of birth
- Email address
- Postal address
- Telephone number
- Volunteer role details / interests
- Terms of office / volunteer period
- DBS details and / or declarations relating to criminal convictions, bankruptcy, vulnerable adult or child barring list information etc that determine volunteer eligibility
- Declared conflicts of interest and loyalty
- Reference information
- Your emergency contacts
- Photograph (where relevant, e.g. Board of Trustees profiles feature on our website)
- Health information where relevant to the volunteer role e.g. if you are attending an event where a health matter should be declared for health and safety reasons
- Details of your qualifications
- Your application information

- Records of complaints
- Information needed for equal opportunities monitoring (we will always ensure that the data is anonymised and kept confidential)
- Your volunteer data protection and confidentiality agreement (where relevant)
- Your branch or support group declaration where relevant
- Your HD voice contract / agreement (where relevant)
- Details of your bank account (for payment of expenses)
- Correspondence with you e.g. letters about your role

We will use this information to do the following as relevant:

- To fulfil our responsibilities to you as a volunteer for the Huntington's Disease Association
- To comply with legal requirements, such as the health and safety at work legislation
- To pursue our legitimate business interests
- To perform our rights and obligations related to your volunteering role
- To contact your emergency contact, where necessary and appropriate
- To create a volunteer profile with your interests and preferences so that we only contact you in the most appropriate way and with the most relevant information.

How we keep your personal information safe

We make sure that your information is accessed only by appropriately trained staff, volunteers and approved contractors and third parties. We ensure that any external contractors and third parties we use are comprehensively checked and adhere to a formal agreement in which our expectations and requirements regarding the way in which they manage, collect and access any personal data, are met.

We make sure that there are relevant controls in place on our website and on our data networks to safeguard your personal details. All of our online forms are protected by encryption.

We take appropriate measures to ensure that any personal information you disclose to us is kept secure, accurate and up to date. We have appropriate security measures in place to prevent personal information from being accidentally lost, used or accessed in an unauthorised way. We limit access to your personal information to those who have a genuine business need to know it. Those processing your information will do so only in an authorised manner and are subject to a duty of confidentiality.

We may disclose personal data when obliged to do so by law, or the disclosure is 'necessary' for purposes of national security, taxation and criminal investigation, or if we have your consent.

How long do we keep your information

We ensure that your personal information is kept only for so long as is necessary and for the purposes for which it was collected.

Retention periods for all data we hold are detailed in our data retention and destruction schedule which is reviewed annually and secure information destruction processes implemented where relevant.

Accessing your information

You have the right to find out what information we hold about you, how this information is used and how long your data is kept. You also have a right to request a copy of the information that we hold about you. If you would like further information or you would like a copy of the information we hold, please contact us via telephone on 0151 331 5444, by email info@hda.org.uk, or write to us at Huntington's Disease Association, Liverpool Science Park, IC1, 131 Mount Pleasant, Liverpool, L3 5TF.

We want to make sure your information is up to date, so please contact us to ask us to correct it if it needs updating.

If you are unhappy about how we handle your personal information, you can contact the Information Commissioner's Office. For further information please visit the Information Commissioner's website www.ico.org.uk or call 0303 123 1113.