# Fundraising at Huntington's Disease Association

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# Fundraising at Huntington’s Disease Association

Fundraising is an integral part of our work at the Huntington’s Disease Association. As of May 2019, the fundraising team at the Huntington’s Disease Association consists of four members.

- Head of Fundraising
- Trust and Foundations Fundraiser
- Community Fundraiser Co-ordinator
- Fundraising Assistant

The Huntington’s Disease Association is a member of the following professional bodies:

- Institute of Fundraising
- NCVO
- Fundraising Regulator

These organisations offer guidance and support to UK-based organisations on all aspects of fundraising and charity governance.

We are registered with the Charity Commission and operate under their guidance and processes.

The information contained in these documents is written in accordance with guidelines from these organisations as well as the professional opinion of the current Head of Fundraising – it has been agreed and signed off by the HDA management team and the Executive Committee (EC). It is recommended that this document is reviewed every two years.

Our work at Huntington’s Disease Association is underpinned by the following,

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| Vision | A better life for anyone affected by Huntington’s |
| Mission | To enable everyone affected by Huntington’s disease to live life to their full potential by:<br>• Improving care and support<br>• Educating families and the professionals who work with them<br>• Championing the needs of the Huntington’s community<br>• influencing decision makers |
| Values | We are<br>• Tenacious<br>• Experienced<br>• Compassionate<br>• Inclusive |

In this document, fundraising refers to the many different ways in which we operate to raise funds to support our work, including fundraising with individuals, Trusts and Foundations, groups & associations and companies. We also work in a commercial and trade capacity to generate income through our specialised courses and online shop.

Through our fundraising we aim to give supporters the best donor experience possible, so that we can raise more funds to benefit more people affected by Huntington's disease. In addition, our fundraising practices are driven by our Supporter Charter, which is underlined by the following principles,

- Transparency
- Commitment to highest standards of practice
- Respect

## Why we raise funds

The Huntington's Disease Association supports anyone affected by Huntington's disease across England and Wales.

We have ambitious strategies and plans to ensure people affected by Huntington's receive the best standards of care and support; in order to deliver these ambitious strategies and plans we have to raise funds. When we raise funds we are raising the profile of Huntington's disease across the general public – whether we work with individuals, groups or companies we raise the voice of people affected by Huntington's disease to those who may not have heard it before.

## How we raise funds

The Institute of Fundraising believes that good fundraising should always be legal, open, honest, respectful and accountable. These are standards we hold ourselves to. We are members of various professional bodies so we can stay up to date with the latest guidance on all aspects of law and governance relating to fundraising including GDPR.

We are clear and transparent; our Supporters Charter lays out how our supporters can expect to work with us to achieve our aim of a better life for everyone affected by Huntington's disease.

The Huntington's community has lived with the stigma of Huntington's for many years; we believe your story is strongest when you tell it. We will help you tell your story so we can engage with supporters and funds who want to support our work. We will treat those who share their story with us with respect and dignity.

## Our funding

Huntington's Disease Association is fortunate to have the support of many people affected by Huntington's disease across England and Wales – and sometimes further afield. We work with individuals, Trusts and Foundations, companies, local authorities and some pharmaceutical companies and when we are allowed to be, we will be open and transparent in recording our funding in a public place, namely our Annual Financial Report. If a donor requests a gift is to be given anonymously we must respect their wishes. We will not risk our independence, credibility or mission in accepting any gifts and reserve the right to refuse any donations which may put us at risk.

## Fundraising and Vulnerable People

We recognise there is a difference in someone being unable to make a decision and someone making what may be considered an unwise decision.

The Institute of Fundraising issued guidance around Mental Capacity and Vulnerable Circumstances in November 2016. We work in accordance with this guidance and Huntington's Disease Association will ensure that our staff,

- Do not accept a donation from an individual we believe to be incapable of making a decision
- If a donation has already been received, we will make a full refund of that donation

We will regularly review our fundraising practices to ensure they are clear and transparent for all our supporters and donors.

## Restricted Funding

The Huntington's Disease Association encourages all supporters to give general, unrestricted funds so we can put all gifts to work as quickly as possible. However, from time to time we may set up specific appeals to fund certain areas of our work including research, specific services, welfare grants, etc. Some of our supporters may also choose to restrict their funding to a specific area of our work which interests them. In this case, we will endeavour to meet the needs of our supporters where reasonably possible, but if it is not possible, we will work with our supporters in a clear and transparent way to ensure their gift goes to where the need is greatest.

Where we do raise funds for restricted activities – SHDA service, HDA events and activities – we will ensure that all funds are restricted accordingly. In line with our general monitoring and evaluation, where we receive grants for our work, we will clearly monitor and evaluate our work, providing clear and concise reporting on the impact the grant has had on our work.

## Raising funds for other Huntington's projects

Huntington's disease, whilst being a rare disease is one which attracts support in many different ways. The Huntington's Disease Association is governed by an Executive Council, which in conjunction with the Management Team, agrees where funds raised are best spent. This is then turned into a Strategy Plan which states the priorities of the charity over the forthcoming years. As a small organisation we can only fund those projects, programmes and research studies agreed in advance through our own internal processes, which are peer-reviewed and support the aims of the Huntington's Disease Association. Whilst we welcome collaborative working we have to ensure that standards across potential collaborative partners meet our own high standards including signing up to Data Protection and GDPR, the Fundraising Code of Practice and the Charity Commission.

## Feedback and Complaints

We welcome feedback on our fundraising activities and refer you to our Fundraising Complaints Procedure.

## Support Charter

Our Supporter Charter lays out our promise to our supporters to ensure we work with you in an honest and transparent manner.

Prepared May 2019 by Head of Fundraising
Signed off by Management Team – June 2019
Signed off by Executive Committee – August 2019
Review – May 2021