

Branch Handbook



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Huntington's disease

Huntington's disease is a genetic disease that damages the brain over time and can affect movement, thinking processes and mental health.

Around 800 people in Scotland were living with the symptoms of Huntington's disease. A further 3200 were estimated to be at risk of developing the disease as a result of inheriting the faulty gene that causes it.

People with the disease can eventually lose the ability to walk, talk, eat, drink and care for themselves: they and all those around them therefore require specialist support from experts who understand the condition.



Scottish Huntington's Association

Scottish Huntington's Association is the only organisation in the country dedicated exclusively to the care and support of the Huntington's community.

The Scotland-wide Scottish Huntington's Association was set up in 1989 by families living with Huntington's to support individuals and families at risk of, or living with, the disease.

Scottish Huntington's Association is both a charity registered with the Office of the Scottish Charity Regulator (charity number SC010985) and a company limited by guarantee, registered with Companies House (number 121496). It is also a membership organisation, regularly communicating with members via its website and annual Family Gathering, and routinely holding an AGM which all registered members are invited to attend.

The charity is run by a CEO at the head of a leadership team, and governed by a [Board of Directors and Trustees](#) who bear the ultimate responsibility for everything the Association does and how it does it. The Trustees – all of whom are volunteers – have a duty to ensure that all activities conform to charity law, regulations and norms, as well as to the terms of Scottish Huntington's Association Articles and Memorandum of Association, two legally binding documents that, together, define Scottish Huntington's Association, its purpose and the way it works.

Since 1989, the charity has grown in size and prominence, while successfully campaigning for improvements in the treatment and support of those affected by Huntington's disease right across the country.

Landmark achievements include the implementation of the world's only [National Care Framework For Huntington's Disease](#), developed in partnership with the Scottish Government and NHS Boards, and the establishment of a nationwide network of specialist services delivered by Scottish Huntington's Association for those who need them.

These include the [HD Specialist Service](#) (1154 individual users and 900 families supported in 2024), [Youth Service](#) (201 users) and the [Financial Wellbeing Service](#) (316 users). Scottish Huntington's Association also provides welfare grants and funds short breaks for individuals and families who need them.

The charity raises money to pay for its role in providing all these services across the country and aims to continue their growth and improvement.

Important facts about Scottish Huntington's Association and its operations today include:

1. People impacted by Huntington's disease need specialist services to cope with a severe and complex disease, its impact on families and a lack of awareness amongst health and social care providers and the wider public.
2. Scottish Huntington's Association is the only organisation in the country exclusively dedicated to providing expert and personalised support for those impacted by Huntington's disease.
3. Our personalised support reduces unnecessary hospital admissions; supports carers and other family members; lowers household poverty; and alleviates wellbeing risks to children and young people living within families impacted by Huntington's disease.
4. We are commissioned by NHS Boards and Health and Social Care Partnerships throughout the country to share our expertise with frontline staff and build support for improved services and higher standards of care for every individual and family impacted by this devastating disease.
5. Scottish Huntington's Association plays a full and active role in attracting the global research community to Scotland to work in partnership with us to improve the lives of families impacted by Huntington's disease.



Our Vision, Mission and Values



These core principles underpin our work and how we do it

Our Vision

The best possible care and support for everyone impacted by Huntington's disease in Scotland.

Our Mission

To fight tirelessly to ensure that everyone impacted by Huntington's disease in Scotland has access to the specialist care and support they need when they need it, regardless of where they live.

Our Values

Respect

We respect the dignity, rights and circumstance of everyone impacted by Huntington's disease, ensuring the support we provide is personalised, sensitive, informed by them and empowering to them.



Collaboration

We listen to families and build trusting and lasting relationships that enable us to shape services, engage and work in partnership with external bodies - and overcome barriers to ensure the right care and support is in place.



Leadership

We share our knowledge, innovation and influence to increase awareness about Huntington's disease and the needs of families to develop bespoke care, advance research and to improve the lives of everyone whose life is impacted by Huntington's disease.



Tenacity

We don't give up. Families rely on our expertise, professionalism and resilience to navigate challenges and find solutions that work for them as individuals, as families and as a community.



Integrity

We deliver on our promises and commitments: to families through the delivery of high-quality services and advocacy on their behalf; to partner organisations by the promotion of best practice and knowledge sharing; to volunteers, donors and funding bodies through responsible stewardship that maximises the impact of all income entrusted to us.



Scottish Huntington's Association Branches

Under the Memorandum and Articles of Association that set up the charity, there is provision for groups of Scottish Huntington's Association members and others to "form themselves into a Branch of the Association, provided that:

- i. "They collectively agree to accept and abide by the conditions set out in the Memorandum and Articles of Association of the Company.
- ii. "They collectively support the objects of the Company as set out in the Memorandum of Association.
- iii. "Any branch so formed will be known as the Branch: Scottish Huntington's Association."

The requirements relevant to branches are contained in Articles 21 to 31, the content of which is reflected throughout this handbook.

Families living with Huntington's disease have always played an important part in the work of Scottish Huntington's Association and they are encouraged to keep in touch with Scottish Huntington's Association national activities through the organisation's website and newsletters.

Registered members of the Association also receive updates every year at a Family Gathering, as well as having the right to attend and vote at an Annual General Meeting.

Branch Handbook

The Scottish Huntington's Association Branch Handbook is designed to provide clear and easy-to-use guidance on both setting up and running a Scottish Huntington's Association Branch. It gives essential information to ensure that a branch makes a meaningful and lasting difference to the lives of people with Huntington's disease, their carers, families and friends throughout Scotland. It also supports branches to observe good practice for the charitable sector, remain within the law, and contribute to the excellent reputation of Scottish Huntington's Association.

The handbook will be of particular use to the Branch Committee, which consists of a Chairperson, Secretary and Treasurer, whilst also giving guidance to Huntington's family members who are considering setting up a Branch. A copy of the handbook will be sent to the Chair of each inaugurated branch, who should ensure its circulation locally, so that committee members and other volunteers who support the branch may use it as a point of reference. Scottish Huntington's Association staff and the Board of Trustees will also use the handbook to help them work alongside the branches. If you have any questions about the content or interpretation of the handbook, contact sha-admin@hdscotland.org and your question will be forwarded to someone who can help.

The handbook is reviewed and updated regularly, in consultation with existing branches, Scottish Huntington's Association staff and trustees. It is complemented by training from time to time, as well as inter-branch meetings with selected trustees and members of the charity's leadership team.

Constitution and membership

Branches are groups constituted under the Memorandum and Articles of Association mentioned above and are an important part of the support network provided by Scottish Huntington's Association. They are run autonomously by their own members and are accountable to the Board of Trustees, which has a responsibility to ensure that branches operate within the law and the strategic policy framework of the charity.

Membership of branches is open to all members of Scottish Huntington's Association; however, branch members are not automatically members of Scottish Huntington's Association and are encouraged to become Scottish Huntington's Association members by completing a membership registration form, available on the organisation's webpage. Branch members' details are kept by the Branch and Scottish Huntington's Association for the purpose of contacting them with news and events of interest to them. An individual can withdraw from membership at any time by contacting their Branch and Scottish Huntington's Association.

All Branches are required to follow Scottish Huntington's Association brand guidelines, including appropriate use of logos and Registered Charity number, and must fulfil the charity's Mission, Vision and Values as expressed on the Scottish Huntington's Association website and quoted above.

Branch Officers have a duty both to support their Branch members and to act in the interests of the Scottish Huntington's Association as a whole.



Why form a Branch?



Branches fulfil an important role by providing help and support at a local level and can be a huge source of interaction for a person with Huntington's disease, their families, carers and friends throughout Scotland.

They are run by volunteers, who may have a personal involvement in living with Huntington's disease.

Branches also form a vital link both with their local HD Specialist Service and with other teams including the Youth Service, Financial Wellbeing Service, Finance, Communications and Income Generation.

Scottish Huntington's Association aims to ensure that the people who run Branches are given support to make the Branches lively and effective. Branch Officers and committee members are encouraged to keep in close regular touch with their local HD Specialist, and to contact staff in the wider organisation whenever new ideas, queries or concerns arise.

Key contacts can be found on the Scottish Huntington's Association website, or questions can be channelled through Executive Assistant Paula Richmond at paula.richmond@hdscotland.org.

In addition, the Chair of the Board Sub-Group on Governance and Succession is happy to discuss branch matters and to support and advise where possible.

Purpose of a Branch

The main purpose of a Branch, within the region it covers, is to further Scottish Huntington's Association primary objectives of 'maintaining and developing a comprehensive range of community-based care and support services' for people who have Huntington's disease and their carers, as stated in the Scottish Huntington's Association Memorandum of Association.[1]

In practical terms, this means that Branches' core functions are to:

- Organise meetings on a regular basis (usually monthly, but as a minimum quarterly), for information sharing and mutual support
- Organise social occasions such as a Christmas meal or a summer outing
- Provide information on Huntington's disease to anyone who needs it
- Raise awareness among the general public about Huntington's disease
- Liaise between families, local HD Specialists and Scottish Huntington's Association services as necessary to improve health and lifestyle options for members
- Carry out fundraising, to support both local and national activities
- Utilise locally raised funds as necessary to support members and their families through Welfare Grants

1] Note that the Memorandum and Articles of Association are currently being updated

How to form a Branch

The initial step is to contact sha-admin@hdscotland.org where staff will direct you to someone who can offer guidance and help set up an exploratory meeting.

This may be the trustee who convenes the Governance and Succession sub-group of the Board, or another trustee or staff member.

The exploratory meeting

The purpose of the exploratory meeting is to gauge interest.

Local family members and any other relevant people will be invited and informed of the work of Scottish Huntington's Association and the benefits of forming a local branch, as well as the work involved for it to thrive.

If the meeting creates sufficient interest, Scottish Huntington's Association will work with the members towards establishing a voluntary committee made up of a Chairperson, Treasurer and Secretary.



All Committee members must be registered, voting members of Scottish Huntington's Association and, in order to comply with the latest OSCR guidelines, all must sign a declaration confirming that they understand and are fit and proper persons for the roles they are taking on. (The declaration form is available [on our website](#).)

The voluntary Committee must then make a written request to the Board for permission to set up a Scottish Huntington's Association Branch, while demonstrating the need in their area, evidencing that the Branch will be viable, and setting out plans for Branch activities.

Once this has been granted, the voluntary committee becomes the formal Branch Committee, and must achieve the following before the Branch can be officially inaugurated:

- Set up a designated bank account. All transactions processed through designated bank accounts will require a minimum of two signatories/approvers. The account must include the facility for internet banking, with the same bank as the national Scottish Huntington's Association account. To streamline reconciliation processes, the Finance Team at Scottish Huntington's Association National Office should be granted view-only access to all accounts held by Branches.
- Decide on meeting dates, times and venues.
- Set up a secure system for keeping records (e.g. the Branch membership list), minutes and accounts, and begin to archive relevant data in line with Scottish Huntington's Association GDPR policy.
- Confirm that processes and systems are in place to hold financial records for six years after the end of the financial year, retain permanently minutes of meetings etc, and manage more ephemeral material, for example membership lists, which should be updated and the old copies destroyed every one to two years.
- Agree a schedule of future Branch elections, ensuring as far as possible that each office will come up for election on a different date.
- Liaise with Branch members and Scottish Huntington's Association to keep all informed of progress.

At the first inaugurated meeting, an experienced staff member from Scottish Huntington's Association or the Board of Trustees will explain the role of the Branch and its obligations under Scottish Huntington's Association regulations.

Such individuals may also continue to attend meetings when required, to provide information and support. Following inauguration of the Branch, the Branch Committee is elected and re-elected for a period of office of two to four years by the Branch members at their AGM, following a standard nominations process. Template documents and advice about preparing for and running meetings are available on the Scottish Huntington's Association [website](#).

If no members are willing to stand for election or re-election, the Branch will need to consider its future. Scottish Huntington's Association staff and trustees are available to assist by discussing any specific local issues or concerns with the Branch committee, including the possibility that a Branch may need to close.

Branch meetings

The initial focus is to find a suitable accessible venue for the regular branch meetings.

The meetings provide opportunities for mutual support and social activities and can include a speaker and / or entertainment or just a catch-up and social support. Branches can also run a range of events, which may be social, fundraising, promotional, educational or a mixture.

They may also be involved in seeking to raise public awareness and to improve local services for people with Huntington's disease, those at risk, and their family, representatives or carers.



Branch Committee

The aim of the Branch Committee is to work towards establishing and maintaining the inaugurated branch in an efficient, representative, fair and transparent manner. Branch business will be administered by the Branch Committee.

To ensure continuity, it is recommended that Branches set up their committee in such a way as to ensure rotation among key office-bearing roles, for example avoiding the situation where all three key offices come up for election at the same time. It is also important to ensure change and diversity among office holders, and to give as many members as possible the opportunity to stand for office. While it is in the nature of a Scottish Huntington's Association Branch that several members of the same family may naturally be active, Branches should bear in mind the need for its Committee to represent the entirety of its members, and avoid simultaneously electing several Committee members from the same family, if possible.

Like other organisations across Scotland, charities are increasingly expected to have regard at every level for both equality, diversity and inclusivity, and sustainability. The Branch Committee is therefore encouraged to consider the steps it can take to ensure that the Branch is as fair, as welcoming and as inclusive as possible, and to protect the environment. Scottish Huntington's Association is developing an approach to both topics and will share material with Branches as appropriate.

Role of the Branch Officers

Chairperson

- Lead and guide the branch and ensure its work is carried out sensitively and effectively
- Maintain good communications between the Branch Committee, Branch Members, local HD Specialist services and Scottish Huntington's Association.
- Lead the agenda and chair meetings, including local Branch meetings, committee meetings (which should normally be held at least quarterly) and AGMs.
- Be a signatory as required in financial transactions.
- Send a short report annually to the Scottish Huntington's Association AGM (typically late autumn) outlining Branch activities in the course of the year and summarising the state of the Branch's finances and membership. This report may be the same as, or a digest of, reports received by the Branch AGM, if the timing of the two meetings permits. Reports can be sent to sha-admin@hdscotland.org.

Treasurer

- Provide accounting support to the Branch
- Maintain an overview of finances and ensure all spending plans and activities remain within budget
- Ensure that financial transactions are recorded accurately and in time to provide regular reports at meetings, e.g. committee meetings and the Branch AGM, each of which should receive a report on financial activities over the period since the last meeting
- Submit a Branch income and expenditure form to the Scottish Huntington's Association Finance Team, four times per year as detailed below (See Scottish Huntington's Association Branch Funds, Financial Aspects of Fundraising, and Financial Reporting) and in accordance with the Scottish Huntington's Association auditors' recommendations.
- Transfer to the Finance Team any local holdings over the sum of £10,000 at the end of the financial year for the purpose of supporting families across Scotland, for example, by funding clinical services, the Youth Service and the Financial Wellbeing Service.

Secretary

- Carry out proper administration of Branch affairs, including maintaining a list of members and contact details, and sharing the list with Scottish Huntington's Association to ensure people receive appropriate communications
- Handle post, which may include money transactions
- Respond to Branch enquiries and circulate communications as required
- Store paperwork and publications according to GDPR requirements
- Manage confidential data according to legal requirements
- Schedule, organise, and handle all paperwork for Branch, committee and AGMs, including ensuring that proper minutes and records are kept.

Purpose of the Branch Committee

The committee's purpose is to help the Branch achieve its objectives through managing its activities effectively. To do this the committee should carry out the following functions:

- Agree the main objectives for the Branch, in line with the purpose of the Scottish Huntington's Association
- Arrange and run a programme of events
- Represent members' views
- Manage the Branch's finances and assets, including preparation of spending plans and year end accounts
- Recruit members and encourage them to stay involved, for example by regularly consulting Branch members about the most popular and helpful activities
- Work in partnership as appropriate, and with the support of Scottish Huntington's Association National Office staff, with other local organisations, and people who can support the work of the Scottish Huntington's Association – for example, health and social services, other voluntary organisations, the local authority, local councillors and, with the support of the Scottish Huntington's Association Communications Team, the media
- Ensure that all members are treated fairly, respectfully and with dignity, ensuring that they are given choices and invited to participate in the running of the branch
- Encourage Branch members to become voting Scottish Huntington's Association members and inform them that their details will be shared with Scottish Huntington's Association National Office for purposes of information sharing in accordance with GDPR legislation. Membership forms are available on the [Scottish Huntington's Association website](#).
- Mentor branch members with a view to encouraging them to stand for election to the Branch Committee in due course
- Take responsibility for ensuring that the activities of the Branch fall within legal requirements and good practice as set out by OSCR, the SCVO and Scottish Huntington's Association Memorandum and Articles of Association. Members of Scottish Huntington's Association staff are available to help whenever committee members are in doubt.

Scottish Huntington's Association Articles of Association make provision for a Branch member to be removed in the unlikely event that this becomes necessary. The Committee should consult the relevant Articles before taking any action: a link is available in the appendix to this handbook.

Annual General Meeting

A Branch must hold an annual general meeting (AGM) within no fewer than 11 and no more than 15 months of the last AGM, with the Chairperson presiding.

The Secretary should announce the meeting, giving no fewer than 21 days' notice of the meeting and stating where and when it is to be held. They will also distribute papers in advance, including the agenda and previous year's minutes for approval.

At the meeting, each of the key office bearers should present a short report on the status of the Branch from the perspective of their particular role:

- The Chair will focus on general activities and direction of the Branch
- The Secretary on membership, events and operational matters, including any elections
- The Treasurer on the financial health of the Branch and an analysis of income and expenditure over the year
- Template reports, which are not prescriptive, are available by request

The agenda may include electing or re-electing a new Branch Committee. This should involve nomination of candidates by two members or associate members of Scottish Huntington's Association, ideally in advance of the meeting but at the meeting itself if this is not possible.

The manner of balloting should however be decided in advance and communicated to members before the election process begins. Best practice in these matters is to hold a secret ballot (a folded sheet of paper is sufficient) if two or more candidates are standing for a single position.

Meetings may conclude with Any Other Competent Business at the discretion of the Chair.



Extraordinary General Meeting

An extraordinary general meeting may be called by the Chair or another member of the Committee if the Chair deems such a meeting necessary, or if four or more members of the branch request it. An extraordinary meeting will normally be held to discuss a single issue, which should be notified to members in advance in the same way as for an AGM. The meeting should be run much as an AGM, with the Chair or another Branch Officer presiding, and should be minuted in the usual way.

Because extraordinary general meetings may need to be held relatively urgently, the period of notice for these meetings may be 10 days rather than the usual 21 for an AGM.

Fundraising: legal and practical aspects

Fundraising supports everything Scottish Huntington's Association does, from paying specialist salaries to financing the award-winning Youth Service. Over many years, Branches have made a tremendous contribution to these efforts by raising funds for the benefit of Huntington's families both in their own areas and across Scotland.

However it is important to recognise that over the years fundraising has also become subject to an increasing number of legal/statutory requirements. Scottish Huntington's Association will support Branches in navigating these complexities to ensure that they do not become an obstacle. In this context, the following guidelines should be observed, to keep Branches on the right side of the law.

- It is the responsibility of anyone raising funds within a Branch to ensure that good practice is observed at every stage of a fundraising venture. Some things to bear in mind are:
- Does all publicity use the approved Scottish Huntington's Association logo, charity number and branding?
- Is it absolutely clear to all potential donors that you are raising funds 'in aid of' or 'on behalf of' Scottish Huntington's Association? Please note that the wording and logo you use are important; therefore, you should seek guidance by emailing fundraising@hdscotland.org if you are unsure what to say.
- Have you made proper arrangements for handling money and placing it in the correct account?

- Have you made arrangements to collect Gift Aid, which can make a significant difference to the amount you raise? You can get advice on how to do this from the Finance Team at Scottish Huntington's Association.
- Have you checked that you have the appropriate insurance in place, for yourself and anyone else, or any property, that may be involved in your activity?
- Have you confirmed that your activity complies with all relevant laws, including the Gambling Act 2005 and the 2005 Charities and Trustees Investment (Scotland) Act 2005?
- Have you got any relevant local authority permissions?
- Have you decided how to handle any personal data you collect in the course of the activity, including photos and video footage?
- Have you made the Scottish Huntington's Association Income Generation department aware of your activity by emailing fundraising@hdscotland.org and worked with the Communications Team on your publicity materials by emailing roisin.eadie@hdscotland.org?

Scottish Huntington's Association has produced [A Guide To Fundraising](#), information for fundraising volunteers which Branches are welcome to use, and which addresses some of the issues raised above. For any queries, please contact the Fundraising Team at fundraising@hdscotland.org.

Scottish Huntington's Association Branch funds, financial aspects of fundraising, and financial reporting

As noted above, Scottish Huntington's Association Branches are encouraged to fundraise. This activity also raises awareness of Huntington's disease and the work of Scottish Huntington's Association. The key guidelines regarding responsibilities for managing financial aspects of fundraising activities, how any funds are used, and financial reporting requirements are set out below.

1. The Branch Committee is responsible for ensuring that fundraising activities are undertaken in compliance with Scottish Huntington's Association fundraising policies.
2. Branch Officers have both the responsibility and autonomy to use money raised for the benefit of those living with, or impacted by, Huntington's disease, providing that those benefits are in alignment with the purposes set out in the charity's Memorandum and Articles and underpinned by the charity's Vision, Mission, Values and Strategy.



3. The Scottish Huntington's Association Board of Trustees has the final responsibility and decision-making authority in the event of any dispute about the use of Branch funds.

4. All money raised by the Branch belongs to Scottish Huntington's Association. However, the Board of Trustees delegates the responsibility of the day-to-day management of those funds to the Branch Officers.

5. In line with limits agreed with Scottish Huntington's Association statutory auditors, Branches may hold up to a maximum of £10,000 within their accounts. Any amounts greater than this £10,000 limit must be transferred to Scottish Huntington's Association central bank account at the end of each financial year (the 31 March return), to be available to support those living with, or impacted by, Huntington's disease throughout Scotland.

6. If a Branch is contemplating fundraising for a specific project that would require it temporarily to hold marginally more than £10,000, the Branch must consult the Scottish Huntington's Association Finance Team well in advance to ensure that all legal and financial details are understood and in order, and so that Scottish Huntington's Association statutory auditors may be advised/consulted as necessary.

7. Plans to fundraise for larger projects that would take the Branch account over £10,000 must be submitted to the Board of Trustees for approval. Any monies raised in this context will be ringfenced and held by the Scottish Huntington's Association Finance Team.

8. Generally, all funds raised by the Branch are classified in Scottish Huntington's Association books and records as unrestricted funds which means that the funds can be used on any purpose deemed appropriate within the guidelines mentioned above.

9. Where funds are transferred to Scottish Huntington's Association's central bank account because they are in excess of the £10,000 limit, these funds will generally find their way back to the Branch in any case because – along with other monies raised by the Association – they will go towards clinical, youth or financial wellbeing services used by local members, as well as supporting national awareness-raising, lobbying and other activities that benefit the entire Scottish Huntington's community.

10. Branch Treasurers are responsible for maintaining an accurate income and expenditure account of all the financial transactions that occur during the year and reporting the details to the Scottish Huntington's Association Finance Team in National Office each quarter (1 January – 31 March; 1 April – 30 June; 1 July – 30 September; 1 October – 31 December).

The quarterly Branch Income and Expenditure Form is completed by the Branch Treasurer and is signed off by two approved signatories. The following documentation should also accompany the form:

- All relevant bank statements
- Receipts for any expenditures incurred in the relevant period
- Any Welfare Grant forms to support payments made in the relevant period (Branches should not keep copies of these after they have been sent to the Finance Team for the quarterly accounts)

In order to capture income and expenditure details on a consistent classification basis, a list of categories and descriptors is included via the link included at the end of this document.

A checklist on the Branch Income and Expenditure Form details the essential documents required. The Finance Team within National Office will book the income and expenditure details into the ledger – subject to there being adequate documentation to support the classifications of income and expenditures.



Schedule of filing dates

Due dates for filing to the Finance Team in National Office:

14 April

1 January – 31 March

14 July

1 April – 30 June

14 October

1 July – 30 September

14 January

1 October – 31 December

A downloadable copy of the Branch Income and Expenditure Form is available by request.

If the Branch has any questions while completing its quarterly return it is encouraged to contact the Scottish Huntington's Association Finance team prior to submission, to minimise any questions once the documentation is received.

Use of Branch funds

Branch funds may, for example, be used for:

- Arranging outings or short breaks where these would be of significant benefit to those concerned and no other funds are available
- Funding respite care and purchasing equipment
- Welfare Grant payments (using the Welfare Grants form)
- Meetings and other events
- Running costs
- Reimbursing out of pocket expenses incurred on behalf of the Branch
- Specific projects that have been considered and approved by the Branch Committee



In the event of a Branch closure

Should a decision be taken to close down a Branch, all liabilities should be settled, any remaining monies contained in its accounts must be transferred to Scottish Huntington's Association, and the Branch bank accounts must be closed.

The Branch Committee (ideally the outgoing Treasurer) should contact the Scottish Huntington's Association Finance team for advice and guidance during this process to ensure all appropriate steps are taken.



Data Protection

Branches must comply with the Scottish Huntington's Association's current Data Protection Policy which reflects the General Data Protection Regulations that came into force on 25 May 2018.

The policy is available on request from Communications Lead [Roisín Eadie](#) in the National Office, and Branch Committees and volunteers engaged in relevant activities must read, understand and apply it. This is a legal requirement.

To give Branches a flavour of what is covered by the policy, the following are things Branches must do in order to meet the legal requirements:

- You must obtain consent to store personal information of members (names, addresses, etc.) Links to the Branch Consent Form and Mailing List Consent Form are provided by request.
- If you do not have up-to-date consents, you should contact all members of the Branch and ask them to complete the Consent to Scottish Huntington's Association Information' Form. In this context, 'up-to-date' means within the last three years; consent should therefore be renewed every three years.
- If you have information about an individual who has ceased to be a member of the Branch and has not been a member for more than six years, for example by withdrawing or by failing to respond to a request to update membership records, you must destroy that information, e.g. shred all paper-based information and delete all electronic information.
- You must not keep any sensitive information, for example about a Branch member's health.
- You must not share any personal information you hold about your members with any other third party, unless you have explicit written permission.
- You must make sure the information you hold about members is up-to-date and accurate. A good way to do this is to conduct a routine review of the information you have at the end of each year. Note that HD Specialist staff do not have automatic permissions to share clients' information with Branch Committees.
- You must make sure any information about members is held securely. Paper-based information should be kept in a locked place and electronic information (e.g. a list of names and addresses) must be password protected.
- You will need to tell members how you will use their personal information (e.g. in order to contact them about meetings).

- You must not use the personal information you gather for any purpose other than that for which consent was given (e.g. you cannot use a mailing list of members to send information about a non-Scottish Huntington's Association-related event that you would like people to attend).
- You should be prepared to disclose what information you hold about a member to that person. This is called a 'subject access request'. Individuals have the right to ask (in writing) for this information, free of charge, and the Branch Chair must respond within thirty days.

Training in compliance with GDPR is available for Branch Officers and volunteers and should be undertaken both on first appointment and thereafter as an annual 'refresher'. Please approach Executive Assistant Paula Richmond (paula.richmond@hdscotland.org) for assistance in scheduling a training session or access to a training video.



Welfare Grants

Welfare grants may be issued by Branches from their own funds to help individuals and families with Huntington's disease who are experiencing a particular difficulty or crisis. For help with setting up a dedicated budget heading for this purpose, Treasurers may wish to contact the Finance department of Scottish Huntington's Association.

In deciding whether to award a grant, it is essential to follow a clear and fair process. It is good practice for such decisions to be taken jointly by at least two people, and for the process to be transparent to all concerned. Conflicts of interest should be avoided (e.g. a Committee member judging an application from their own family). At the same time, it is important that the process should not be overly bureaucratic, in order to allow decisions to be made swiftly and without an undue burden of paperwork.

The Welfare Grant form assists the process in all of these respects. It should be issued and endorsed by an HD Specialist or health professional who has been involved in supporting the person or family applying for the grant. On receipt of the application, the Branch Committee will give it careful consideration and successful applicants should receive the grant within a relatively short time.

The Welfare Grant must not exceed a maximum of £300 for an individual and £500 for a household in any one year. This ensures that as many people as possible will benefit from a grant award.

Confidentiality

- Everyone involved with the Branch must understand and respect the need for confidentiality in relation to their roles, in particular, Welfare Grants.
- Information given in confidence from an individual or family member, which should not be used or disclosed in a form that might identify them without their consent.
- Use of pictures, photographs, videos, audio-tapes or other representations of anyone without their written consent. A link to the Consent Form is available by request.

Communications and brand

All Branches must follow Scottish Huntington's Association Brand Guidelines detailing use of logo, colours and key messages. The following details, including our Registered Charity Number, should also be included in all publications and promotional materials developed by the Branch:

Registered with and regulated by the Office of the Scottish Charity Regulator No: SC010985, Scottish Huntington's Association is a wholly Scottish charity and is registered in Scotland as a company No: 121496. Registered Office: Business First, Burnbrae Road, Paisley, PA1 2FB

Please contact the Communications Lead (roisin.eadie@hdscotland.org) to access the Brand Manual as well as receiving support and guidance.

SHAre magazine is published on our website three times a year and is distributed by email to all consenting Scottish Huntington's Association and Branch members, clients and supporters who have requested to receive it.

Branch members also receive regular email bulletins from Scottish Huntington's Association with news of the latest developments at the charity, ways to get involved, upcoming events, and updates from each of the Branches.

The charity also publishes leaflets and booklets which can be requested from National Office at sha-admin@hdscotland.org or downloaded from our website. Further information is also shared with families, supporters, stakeholders and other organisations on Facebook (ScottishHuntingtonsAssociation), X (ScottishHD), Instagram (scottishhuntingtons) and LinkedIn (Scottish Huntington's Association).

Some Branches choose to set up their own social media pages: please get in touch with Communications Lead Roisin Eadie (roisin.eadie@hdscotland.org) for advice and support, including guidelines for use.

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