

Huntington's Disease Association

Youth Voice Group Information Pack

Closing date: midnight Monday 31 November 2026

About Huntington's Disease Association

The Huntington's Disease Association help people living with Huntington's disease to live a better life.

We improve care and support services for people with Huntington's disease, educate families and professionals, and champion people's rights.

We have a dedicated Youth Engagement Service (HDYES), who's focus is supporting young people whose families are affected by Huntington's. Our confidential service is for anyone age 8-25 living in a family affected by the disease (including extended family such as a cousin, grandparent, etc).

To find out more about us you can click this link, which will take you to our website.

Overview of the project

We want young people to have an opportunity to shape and develop the services, programmes and resources that we create, so that we can provide the best possible support for young people impacted by Huntington's disease. We are recruiting new members aged **14-25** to join our youth voice project (HDYV) to help make a difference for other young people impacted by Huntington's disease.

You will join up to **15 other young people** in leading change through an annual residential followed by virtual monthly meetings. Our monthly meetings consist of completing project work, sharing ideas about how to improve services for young people and making these ideas a reality. One project currently focuses on social media and creating content to support and help other young people affected by Huntington's disease. These meetings also give you an opportunity to meet other young people affected by Huntington's disease.

We also offer the opportunity to develop your leadership skills through workshops, training and guest speakers. There is the opportunity to be involved in interview style Instagram Lives, which is an optional way to develop your skills and confidence.

The programme will start in **January 2027** with an online meeting to get to know each other and we will then have a **four day residential** activity weekend from **Friday 5 February - Sunday 7 February** to build the team and shape project plans for the year ahead.

You will make new friends, build your confidence, be supported to develop your leadership skills and have a positive impact on other young people with similar experiences to you. Most of all it will be a lot of fun!

All expenses will be covered.

Who we are looking for

We are looking for young people who:

- Are aged 14-25 from across England and Wales
- Have been impacted by Huntington's disease
- Are passionate about making a difference for other young people impacted by Huntington's disease
- Want to meet other like-minded people and develop their skills and confidence

Huntington's Disease Association is committed to Equal Opportunities throughout its work. We actively welcome and encourage applications from diverse groups including all gender identities, sexual orientations, ethnicities, faith groups, those who live with a disability or have parenting or caring responsibilities.

Commitment

We want to make sure this programme is as accessible as possible and we realise you will have other commitments so we are looking for young people who:

- Can attend a **residential induction** weekend in **February 2027**
- Can attend a **minimum of five virtual meetings** a year
- Can attend an **in-person celebration event** towards the **end of 2027**

Optional

- Support our interview style Instagram Lives. This might be answering questions on a topic or interviewing professionals about a topic. You will be supported by staff before, during and after these calls and will be provided with questions before the call.
- Create social media content for our channels. This could involve recording a video or writing a blog post about your experiences.

How to apply

To apply for a place on the project please complete the short application form using the link below:

HD Youth Voice application form 2027

We will be calling all applicants in December to have a short chat about the role before offering places to those who are successful. This gives you the opportunity to hear more about the role and to ask any questions you might have.

Queries and Questions

If you have any queries or would like more info please contact James O'Connor at james.o'connor@hda.org.uk or on 07718424905