JOIN-HD: The Juvenile Onset Huntington’s Disease Registry
Information for Participants

What is the purpose of JOIN-HD?
JOIN-HD is a patient registry which will collect information from individuals who have Juvenile onset Huntington’s Disease (JoHD), and their caregivers from around the world. JoHD is extremely rare, occurring in about 5% of all people with Huntington’s disease. This has made it difficult for researchers to find out more about JoHD. JOIN-HD was created to help researchers find people with JoHD so that they can learn more about this disease.

Who can participate in the JOIN-HD registry?
• Someone who has been diagnosed with JoHD,
• The caregiver of someone with JoHD, or
• A previous caregiver of someone who had JoHD.

What will happen if I may want to participate?
If you are interested in participating, you will be contacted by the JOIN-HD study coordinator. The coordinator will talk to you about the JOIN-HD registry and answer any questions you might have.

If you are eligible to participate, the study coordinator will email you a participant ID number and a link to the JOIN-HD website. JOIN-HD is an electronic registry, so all information collected will use web-based questionnaires. There are two separate ways of taking part in JOIN-HD: as a caregiver or as a patient. If you are taking part as a caregiver, you should complete the online consent and questionnaires yourself. If you are taking part as a patient, you should complete the online consent and questionnaires yourself if possible, or with the help of a caregiver if needed.

The JOIN-HD registry will include multiple stages. You are being invited to take part in Stage 1. In Stage 1, we will be collecting your consent to take part in JOIN-HD, as well as information about the links you have with the Huntington’s disease community. If you agree to take part in Stage 1 you will be invited to take part in later stages of JOIN-HD when they become available.

What will happen if I change my mind?
If you change your mind about taking part in JOIN-HD, you will be able to withdraw at any time. You will not have to give a reason for why you want to withdraw.

Are there any possible benefits from taking part?
We hope that this registry will be beneficial to learning about JoHD in the future. Information collected in JOIN-HD will help us understand more about JoHD so we can advocate for improvements to care, research, and awareness.
Are there any possible risks from taking part?
Describing your personal experiences may bring up upsetting thoughts or feelings. You can take as much time as you need to complete the questionnaires or have a break and come back to it another time. You are always welcome to contact HDYO for support and are free to withdraw from JOIN-HD at any point.

What will happen to my data?
HDYO is responsible for looking after your information and using it properly. All information collected will be kept confidential. Personal information collected when you sign up, like your name and email address, will be stored separately from any other information you provide. Only data managers will have access to that information. The remainder of the information you entered will be assigned a participant ID number so that it will be de-identified, meaning researchers and other people who see the data will not be able to identify you.

What will happen to the results from JOIN-HD?
A summary of the results will be presented at conferences and published in journals. You will not be identified in any of these publications.

Who is organising and funding JOIN-HD?
JOIN-HD has been organised by the Huntington’s Disease Youth Organization (HDYO). It has been funded by a group of industry partners called the HDYO Alliance.

Who has reviewed JOIN-HD?
JOIN-HD has been reviewed by the HDYO Research Committee, the JOIN-HD Scientific Oversight Committee, and the European Huntington’s Disease Network (EHDN).

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Thank you for reading this information sheet and considering taking part.

Information for Participants (v1)