



**HUNTINGTON'S DISEASE  
YOUTH ORGANIZATION**

The Huntington's Disease Youth Organization (HDYO) is looking to employ an experienced Clinical Study Coordinator who will execute, manage, and coordinate JOIN-HD, HDYO's Juvenile-onset Huntington's disease (JoHD) Registry according to the protocol, internal policies/procedures, best practices, and regulations governing clinical research. This remote position will require you to work closely with the HDYO Research Committee, Scientific Oversight Committee and to oversee data and site management.

Salary: £28,000/\$36,600 based on estimated hours worked

Hours: 22.5hours per week

Fixed term contract for 6 months possibility of extension dependent on funding.

Location: Remote from home

Reports to: Executive Director

### **HDYO**

The Huntington's Disease Youth Organization (HDYO) is a non-profit set up to provide support and education to young people (aged up to 35) impacted by Huntington's disease (HD) around the world. We are an official entity in both the USA (501c3) and United Kingdom. Our goal is to provide support and education for young people impacted by HD globally. We do this through providing professional support online, creating educational content for all age groups (kids, teens, young adults, parents, professionals), making our site and content available in as many languages as we can, connecting young people with their peers, holding events such as youth camps and conferences around the world, motivating and providing opportunities for young people to get involved and working with other HD organizations to improve what they offer to young people.

### **The JOIN-HD Registry**

Juvenile-onset HD is defined as the onset of motor symptoms prior to a person's 21st birthday. It is estimated an average 4.92% of all HD cases worldwide are diagnosed as JoHD. Currently there are no disease altering treatments and no clinical trials to date have included the JoHD community. JoHD has many differences compared to adult-onset HD and its naturally history is poorly understood. There is a limited amount of healthcare providers, support, resources, or treatments available for people with JoHD. According to a 2018 HDYO survey, the JoHD community feels underappreciated and undersupported. HDYO's mission is to help young people impacted by HD. This includes young people with JoHD and their families.

The ultimate goal of JOIN-HD is to:

- Build a global community of families impacted by JoHD.
- Increase knowledge of JoHD.
- Facilitate future research.

To achieve this HDYO has partnered with pharmaceutical companies, the HD research community and networks, HD patient advocacy organisations and HD families to assist in designing a registry specific to the needs of those with JoHD.



**SUPPORT, EDUCATE, EMPOWER**

**visit: [en.hdyo.org](http://en.hdyo.org)**



Registered entity in both the United Kingdom (Charity Commission 1145781) and the USA (501c3 EIN: 45-4955538)



HUNTINGTON'S DISEASE  
YOUTH ORGANIZATION

### Responsibilities

The Study Coordinator's primary duties, outlined in more detail below, will require them to work independently, be flexible, and be prepared to use their initiative. Applicants must be able to work well under pressure, be productive under tight timelines with a minimum of supervision, have experience working in a clinical research environment, have excellent communication skills, and be adept at dealing with all staff. The study coordinator will work alongside other staff members and report to the board of volunteer directors.

Specific responsibilities include, but are not limited to:

#### Participants

- Pre-identification, enrollment and follow-up of registry participants.
- Providing ad-hoc triage support to registry participants (and families impacted by JoHD in general).

#### Platform

- Developing a thorough knowledge of the registry electronic data capture (EDC) platform and participating in data implementation meetings and user testing.
- Researching, negotiating and implementing a new EDC platform for the next stage of the registry.
- Conducting ongoing remote data review for research participants in the EDC and providing feedback to HDYO, EDC platform provider, JOIN-HD SOC and other stakeholders.

#### Study management – Progressing to JOIN-HD Stage 2

- Serves as primary contact with research participants, HDYO research committee, JOIN-HD scientific oversight committee (SOC), HDYO partners, and regulatory agencies. Coordinates independently from start-up through close-out.
- Day to day management of project timelines.
- Leads the JOIN-HD registry start-up; to include platform testing, preparation, and submission of ethical review.
- Supports the Principal Investigator (PI) and HDYO staff team in all aspects of clinical study management.
- Contributes to the development of Standard Operation Procedures (SOPs) for the registry.
- Creation of study documents.
- Maintains the Study Master File.
- Produces progress reports for multiple stakeholders detailing current participant recruitment, protocol deviations, data quality and eventually clinical site status.
- Managing translations for Registry materials.
- Takes an active role in designing future stages of the Registry with the PI and SOC.
- Provides ad-hoc study-specific information and analyses as required by the PI, study funder etc.
- Assists with the preparation of manuscripts, abstracts, posters, and oral presentations for national and international meetings, reports, publications, and summaries of trial results.
- Identifies and reporting potential study-related adverse incidents in a timely fashion and in accordance with JOIN-HD registry protocols.

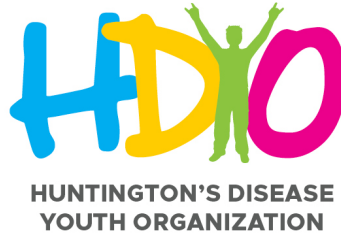


SUPPORT, EDUCATE, EMPOWER

visit: [en.hdyo.org](http://en.hdyo.org)



The Juvenile-Onset Initiative for Huntington's Disease



#### Engagement and Outreach

- Manages the JOIN-HD SOC.
- Supports the JOIN-HD family advisory group in conjunction with SOC.
- Builds relationships with patients and families impacted by JoHD and professional communities.
- Maintains JOIN-HD website.
- Participate in funding applications (JOIN sponsorship & general grants).
- Outreach to HD associations, networks, charities.
- Presents updates on JOIN-HD to stakeholders at scientific and patient community meetings or events.

#### HDYO

- Liaises with members of HDYO Research committee and executive board, HDYO staff members, HDYO funders and partners and multidisciplinary teams (site Principal Investigators, researchers, study coordinators, clinical, administrative staff) to ensure effective running of the registry.
- Works with HDYO team to provide support to JoHD families.

#### Experience and Qualifications

The suitable candidate will have relevant clinical study experience.

- Educates to degree level.

#### Desirable:

- Experience working with paediatric populations.
- A postgraduate qualification (e.g. MSc/PhD).
- Experience with patient registries.

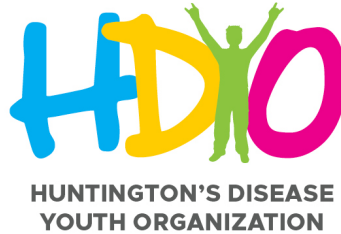
#### Qualities that are important for this position include:

- Ensures essential documentation and recording of patient and research data in appropriate files per institutional and regulatory requirements.
- Ensures confidentiality is maintained as applicable.
- Excellent interpersonal, as well as written and verbal communication skills.
- Strong planning and organizational skills and ability to work in a changing, multiple demand setting to prioritize a large volume of work and meet deadlines efficiently and accurately.

#### General

- As duties and responsibilities change, the job description will be reviewed and amended in consultation with the Study Coordinator.
- The Study Coordinator will carry out any other duties as are within the scope, spirit and purpose of the job as requested by the line manager.





#### Other Opportunities Given Time and Skills

- Additionally relevant training (e.g. GCP (general, Informed Consent in Paediatric Research, Informed Consent with Adults Lacking Capacity), When a Child Dies: Supporting Parents & Families (Child Bereavement UK), Genetic Alliance Registry Bootcamp, Rare Disease Patient Registries (EURORDIS Open Academy), Winter School on Scientific Innovation and Translational Research (EURORDIS), Suzy Lamplugh Personal Safety & Lone Working training (through HDA), Building positive partnerships between patient groups and industry (Beacon for rare disease)
- Leading projects as they came up e.g., scholarships for partner events.
- Writing/proofing e.g., HD clinical research overview on HDYO website, summaries of research/HD news for social media, article editing, BDBs drug development video.
- Keeping up to date with progress in HD (& general rare disease) research (reading articles, attending webinars, conferences etc.)
- HDYO Research video series.
- HDYO Congress and Camps: flights, programme committee, scholarship committee

Interested candidates should send their CV and cover letter to [info@hdyo.org](mailto:info@hdyo.org).



SUPPORT, EDUCATE, EMPOWER

visit: [en.hdyo.org](http://en.hdyo.org)



Registered entity in both the United Kingdom (Charity Commission 1145781) and the USA (501c3 EIN: 45-4955538)