JOIN-HD - Juvenile onset
Huntington's Disease Registry

HDYO has more information about HD available for young people, parents and professionals on our site:

www.hdyo.org
HDYO is proud to launch JOIN-HD, our global patient registry for JoHD patients and their caregivers.

Huntington’s Disease can occur in individuals at any age of their life - young or old. When someone who is 20 or younger develops symptoms of Huntington’s Disease, they are classed as having Juvenile Onset Huntington’s Disease. You can find out more about JoHD in our basics of JHD article.

What is JOIN-HD?
JOIN-HD is a global registry that collects experiences from both young people who have JoHD and their caregivers. All the information people add to the registry helps us understand more about JoHD. This will allow us to advocate for improvements to care, research and awareness. We hope JOIN-HD will be a platform that will encourage other scientists and clinicians to carry out much needed research into this devastating disease.

The information collected is anonymous, so people who are participating can feel safe knowing that their personal information (name, date of birth, where they live) won’t be shared with anyone outside of the JOIN-HD team.

Ultimate Goals
- Improve advocacy, care and support for young people with JoHD and for their families.
- Create a network of leading healthcare JoHD professionals from lots of different specialities
- Speed up research for the JoHD community.
- Learn what people with JoHD and their families need so we can improve support and education programmes.
- Identify support, education and community resource connections for children and young people with JoHD and their families.

This registry is only possible with the generosity of donors and support from sponsors. If you’re interested in learning more, contact registry@hdyo.org

What is a Registry?
JOIN-HD is a type of project called a Patient Registry. These are databases that collect answers to a set of questions from those affected by a particular condition.
are two agencies (EMA covers European Union counties and FDA covers United States of America) who are responsible for ensuring that any medicines, devices or studies are being done safely, effectively and that those taking part are informed and protected. EMA and FDA both have guidelines on how Patient Registry projects should be managed because they support that those affected by conditions are vital to finding new treatments and care. HDYO has made sure that we are working to those guidelines.

- EMA Patient Registry Guidelines Information
- FDA Patient Registry Guidelines Information

**Who is involved in JOIN-HD**

HDYO has partnered with pharmaceutical companies, HD research communities and professional networks, HD patient advocacy organizations, and HD families to design JOIN-HD specifically to the needs of those with JoHD. HDYO has been working on this registry to ensure we include the needs of the community, to prepare the best platform to collect the information, and to establish a first-class scientific oversight committee. The HDYO research committee is the team who manages JOIN-HD. You can find information about our research committee on the HDYO Team page. Our HDYO research committee co-chair, Dr. Lauren Byrne, is the JOIN-HD Chief Investigator. As Chief Investigator, Dr. Byrne is the lead researcher and is responsible for the overall conduct of this important project. Our Clinical Study Coordinator, Dr. Rebecca Mason, oversees the day to day running of JOIN-HD and is the point of contact for anyone wanting to know more.

**Who can participate?**

You can take part in JOIN-HD if one of the below describes you:

- If you are someone who has been diagnosed with JHD
- If you are a caregiver to someone who have been diagnosed with JHD
- If you were a caregiver to someone who had been diagnosed with JHD

**How Do We Get Involved?**

If you would like to participate in JOIN-HD, please read the Participant Information Sheet and pre-register. If you have any questions about JOIN-HD, send us a question by emailing registry@hdyo.org
Scientific Oversight Committee

- **Dr. Rebecca Mason** – JOIN-HD Program Coordinator - email registry@hdyo.org
- **Dr. Lauren Byrne** – JOIN-HD Chief Investigator/HDYO Research Co-Chair
- **Dr. Bonnie Hennig-Trestman** – HDYO Research Co-Chair
- **Dr. Martha Nance** – Medical Director, Struthers Parkinson’s Center, Clinical Professor of Neurology at University of Minnesota and Director of HD Center of Excellences at Hennepin County Medical Center
- **Dr. Jean-Marc Burgunder** – Professor of Neurology, Senior Consultant in Neurogenetics University of Bern
- **Dr. Leon Dure** – Professor & Director of the Division of Pediatric Neurology at the University of Alabama at Birmingham, USA
- **Helen Santini** – Specialist JoHD Adviser for the HDA of England and Wales
- **Dr. Oliver Quarrell** – Consultant Clinical Geneticist and lead facilitator of the EHDN Pediatric HD Working Group
- **Dr. Benjamin Wilfond** – Director of the Treuman Katz Center for Pediatric Bioethics at Seattle Children's Hospital and professor and chief of the Division of Bioethics in the Department of Pediatrics at the University of Washington School of Medicine

Sponsors