



HUNTINGTON'S DISEASE  
YOUTH ORGANIZATION

# What Is HDYO?



SUPPORT, EDUCATE, EMPOWER

[HDYO.ORG](http://HDYO.ORG)

# Who We Are

The Huntington's Disease Youth Organization is an international non-profit supporting, educating and empowering young people up to 35 years who are impacted by Huntington's Disease around the world. We are committed to:

**Support:** Through online support groups, providing first-hand experiences, encouraging open conversations and world-wide resources, support is such a crucial need for this community of young people.

**Educate:** Research and resources continue to evolve every day in the HD community. HDYO provides up to date educational tools in a comprehensible and useful manner.

**Empower:** We strive to erase the stigma around HD and empower young people to advocate for themselves and share their stories.



# Who We Serve



**Young Person:** We consider a young person to be up to the age of 35, and our services are designed for those ages. However, our educational content is useful for all ages, and we encourage anyone to contact us if they need support.

## What do we mean by 'impacted by HD'?

This includes many more people than just the person who has HD. That person is affected by HD, but many people can be impacted by HD who don't have HD at this moment. So impacted by HD, for us, includes:

- At risk for HD
- In a family with HD
- Know someone with HD
- Partner impacted by HD
- Young Person who tested positive or negative for HD
- Diagnosed with HD or JoHD
- Learning about HD for educational purposes
- Feeling concerned about HD for any reason

# By the Numbers

SINCE  
2012

SERVED NEARLY  
**7,000**  
YOUNG PEOPLE & FAMILIES

OVER 90 COUNTRIES

**200,000**  
RESOURCES  
SHARED

**7 MILLION**  
WEBSITE VIEWS

## FOLLOWERS

 +12,600 FOLLOWERS  
 +1,600 FOLLOWERS  
 +2,100 FOLLOWERS

 6,000 SUBSCRIBERS  
2.6 MILLION VIEWS  
 2,000 SUBSCRIBERS

## Support, Educate & Empower

- **JOIN-HD: The Juvenile-Onset Initiative for Huntington's Disease** - A Global Registry to connect the community of those affected by JOHD, increasing the understanding of the disease and encouraging future research.
- **HDYO International Virtual Congress** - A program of insightful talks, sharing, research updates, peer support and fun!
- **Youth Mentorship Program in Partnership with HDSA** - This program provides youth (mentee) with one-on-one time with another person (mentor) who will receive training, and ongoing support
- **International Ambassadors** - Young people who bring real-life experiences to better advocate for the entire community.
- **Research Video Series** - In partnership with HD Buzz, we develop frequent videos to showcase the latest news in HD research.
- **Breaking Down Barriers Series** - We tackle the stigmas surrounding HD
- **Matt's Chats** - Featured interviews with members of the HD community.