



**HUNTINGTON'S DISEASE  
YOUTH ORGANIZATION**

# **2022 Sponsorship Proposal**



**SUPPORT, EDUCATE, EMPOWER**

# 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

# Why We Exist

**There are no medications that can prevent, stop, cure or slow the progression of HD.**

**Juvenile HD usually has a more rapid progression rate than adult onset HD.**

**\*Children with HD parents are 28% more likely to have an adverse childhood event compared to the average child.**

**The conversation around HD needs to be normalized.**

**\*Children in an HD family are more likely to experience parents with psychiatric problems, dysfunction & loss.**

*\* "People who need people, an attachment perspective on hereditary disease" by Lucienne B. van der Meer*

## 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, Education & Empower

## JOIN-HD

JOIN-HD is a global patient registry with the primary aim of identifying and locating people impacted by JoHD. Secondary aims include increasing understanding of JoHD, facilitating future research and identifying unmet needs, to improve advocacy, care and support for patients.



We have recently progressed from Pre-Enrollment Phase to Stage 1 and will be actively recruiting.



## International Congress

A program of insightful talks, sharing, research updates, peer support and fun! This event is aimed primarily at young adults aged 18-35 impacted by HD from families around the world. Our Virtual Congress welcomes HD family members of all ages. It's also for professionals and pharmaceutical industry partners who work with the HD community.

## Youth Mentorship

In partnership with the HDSA, the mentorship program is designed to support young people across the United States who face the everyday challenges of growing up in a family affected by HD. This program provides youth (mentee) with one-on-one time with another person (mentor) who will receive training, and ongoing support from a Youth Social Worker within the HDSA.



# Support, Education & Empower

## Research Series

In partnership with HD Buzz, we develop frequent videos to showcase the latest news in HD research. From the effects of the COVID vaccine to clinical trials, these pieces engage our younger community in a conversational way.

Is an mRNA vaccine dangerous for HD?

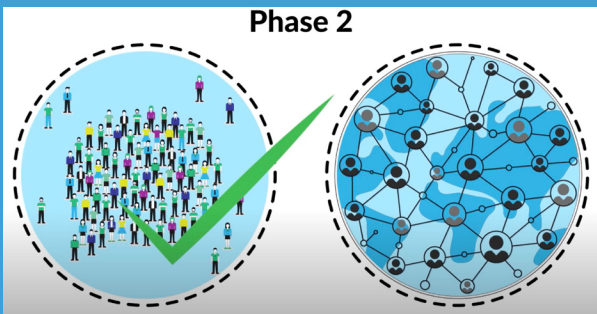


## Breaking Down Barriers

There are many stigmas and gaps in the education surrounding HD. We tackle these topics with our Breaking Down Barriers Series. Topics include:

- Talking to Children about HD
- Access to Health & Research
- Being a Young Caregiver
- What is a Clinical Trial
- Following Young People Throughout Their Journey

Phase 2



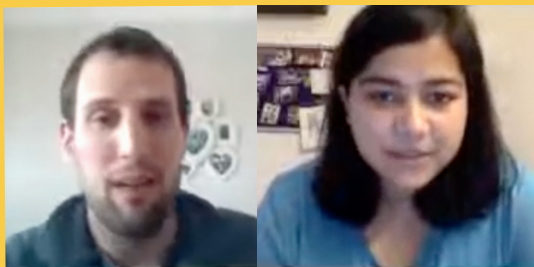
## Ambassadors

Young people across the globe share their experiences to connect the HD community together to show they are not alone. Through Top Tips to sharing their journeys to keeping their fingers on the pulse of the latest in HD, these Ambassadors continue to bring real-life experiences to better advocate for the entire community.



## Matt's Chats

Featured on social media, Matt's Chats features interviews with others in the HD community to discuss topics like juvenile onset HD, deciding to do genetic testing, latest in research and more.



# Sponsorship Opportunities

## Organizational Sponsorships

These packages are a starting point, and we are happy to discuss custom packages, multiple payments and other needs. Organizational Sponsors support the infrastructure needed to support our staple programs.

### Platinum Sponsorship

**\$35,000**

*Includes JOIN-HD, Breaking Down Barriers, Research Series, Online Support Groups, Ambassadors & International Congress*

- Logo placement with hyperlink on HDYO.org
- Logo placement on program advertisements
- Quarterly updates on HDYO email blasts and social media platforms
- Logo on all HDYO email blasts year-round
- Information about trial/company distributed to program participants
- Annual Feature on Matt's Chats
- Dedicated Session during International Congress along with additional sponsorship benefits to match Gold Level

### Gold Sponsorship

**\$20,000**

*Includes JOIN-HD, Breaking Down Barriers, Research Series, Online Support Groups & Ambassadors*

- Logo placement with hyperlink on HDYO.org
- Logo placement on program advertisements
- Bi-Annual updates on HDYO email blasts and social media platforms
- Logo on all HDYO email blasts year-round
- Information about trial/company distributed to program participants

### Silver Sponsorship

**\$10,000**

*Includes Breaking Down Barriers, Research Series, Online Support Groups & Ambassadors*

- Logo placement with hyperlink on HDYO.org
- Logo placement on program advertisements
- Annual update on HDYO email blasts and social media platforms
- Information about trial/company distributed to program participants

# Sponsorship Opportunities

## Program Sponsorships

We are happy to discuss custom packages to include a combination of specific programs without falling into the Organizational Sponsorship.

### JOIN-HD

**\$10,000**

- Logo placement with hyperlink on HDYO.org JOIN-HD site & dissemination
- Logo placement on program advertisements
- Logo on HDYO email blasts when mentioning JOIN-HD
- Access to aggregated data
- Join the HDYO alliance
- Quarterly update meetings
- Opportunity to review questionnaires
- Opportunity for feedback to be presented to the Scientific Oversight Committee

### Youth Mentorship Program

**\$5,000**

- Logo placement with hyperlink on program website
- Logo placement on program advertisements
- Logo on HDYO email blasts and social media when mentioning YMP
- Information about trial/company distributed to program participants
- Quarterly update reports

### Research Series

**\$10,000**

- Logo placement with hyperlink on program pages on HDYO.org
- Logo placement on program advertisements
- Logo on HDYO email blasts and social media when mentioning program
- Logo on each video
- Quarterly update reports

### Ambassador Program

**\$5,000**

- Logo placement with hyperlink on program pages on HDYO.org
- Logo placement on program advertisements
- Logo on HDYO email blasts and social media when mentioning program
- Information about trial/company distributed to program participants
- Quarterly update reports

### Breaking Down Barriers & Matt's Chats

**\$10,000**

- Logo placement with hyperlink on program pages on HDYO.org
- Logo placement on program advertisements
- Logo on HDYO email blasts and social media when mentioning program
- Quarterly update reports