



**HUNTINGTON'S DISEASE  
YOUTH ORGANIZATION**

# **2021 Annual Report**



**SUPPORT, EDUCATE, EMPOWER**



# Commitment to Our Mission

The Huntington's Disease Youth Organization is an international non-profit supporting, educating, and empowering young people up to 35 years, impacted by Huntington's Disease (HD).

Our aim is to provide a safe place to **support, educate & empower** young people & their families. We do this through several online and in-person resources.

## Who We Help:

HD impacts far more people than just those who have the disease. Impacted for us includes -

- At risk for HD
- Young person gene tested with a positive or negative result
- Diagnosed with HD or JoHD
- Those not at risk who have family, loved ones, friends with HD
- Caregivers who may/may not be at risk
- People who know someone with HD
- Learning about HD for educational purposes
- Feeling concerned about HD for any reason

HDYO.org – The center of our support & education.

14 languages & huge range of content for different ages.

Nov 2021, we launched our new redesigned website with the new branding & enhanced navigation.

Direct support is provided by our staff.

### Educational Programs

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 & encouraging future research.

HDYO International Congress - A program of insightful talks, sharing, research updates, peer support & fun!

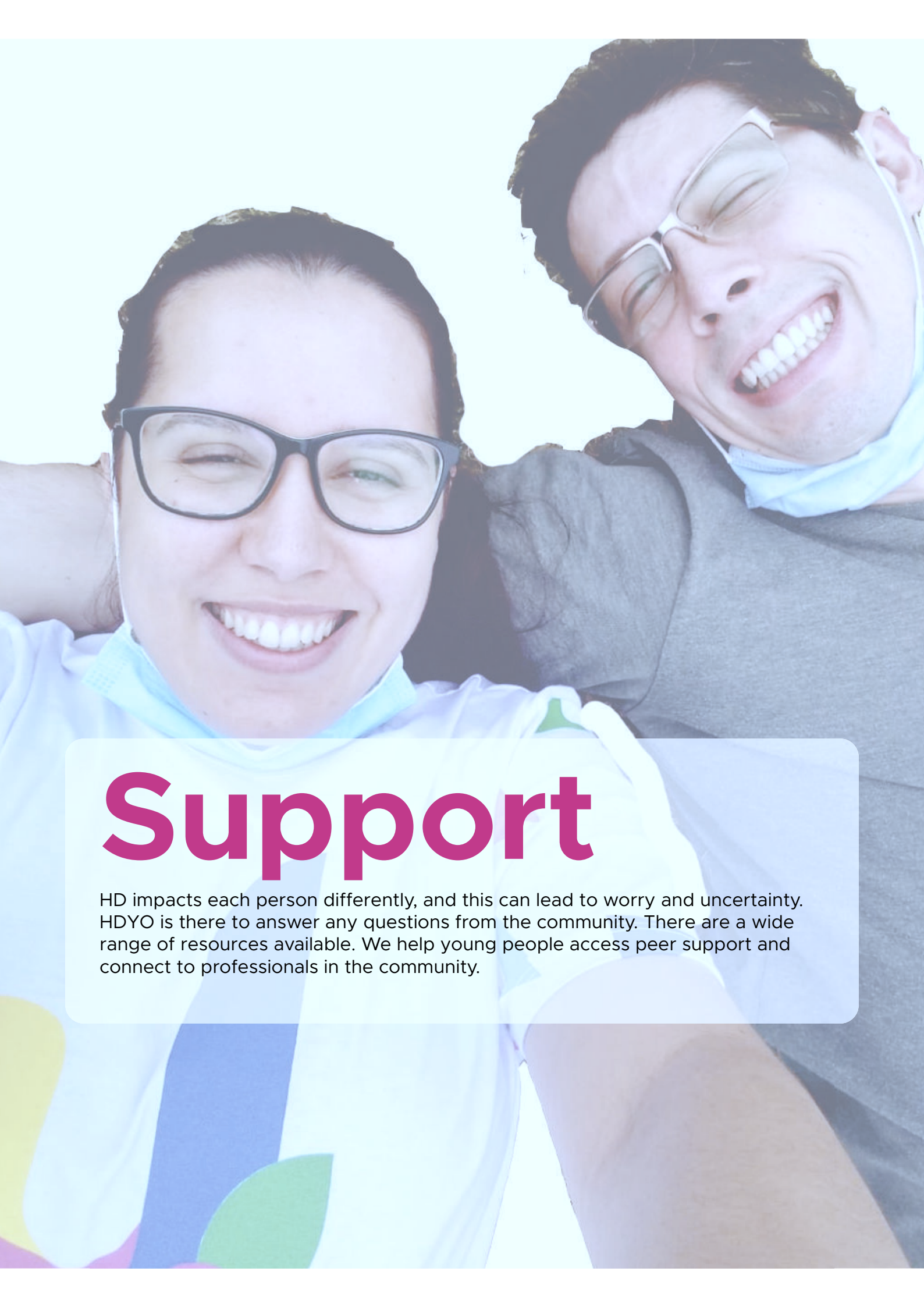
Youth Mentorship Program in Partnership with HDSA - This program provides a young person (mentee) with one-on-one time with another person (mentor) who will receive training, & ongoing support

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

HDYou Community Stories - Featured interviews with members of the HD community.



# Support

HD impacts each person differently, and this can lead to worry and uncertainty. HDYO is there to answer any questions from the community. There are a wide range of resources available. We help young people access peer support and connect to professionals in the community.

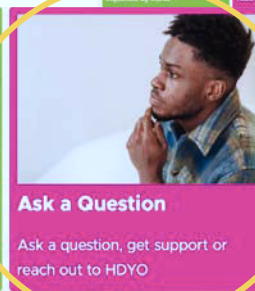
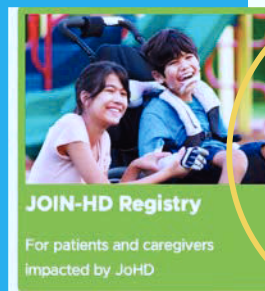
# SUPPLY

## Enhanced Website Navigation & Support

Since HDYO.org was launched, it has provided essential support and education to more than 7 million people across the globe. In 2021, we launched our new updated more engaging visual identity; brighter colors and updated logo. This was implemented on social media first then rolled out across all materials. We then launched our new redesigned website using our new impactful branding. We also took the opportunity to revise the structure, the menus, the tiles and the administrative side to allow for continual content updates. These updates are more welcoming and easier to use for the broad range of young people who need support and resources.

There's still the same great content to help each age group, and we've continued to review articles to ensure they represent the latest in HD needs.

Asking for help, support or advice is also a main focus on HDYO.org as many people need immediate assistance. Our team is here to help!



## From the Community

*Thank you! It's all thanks to you and your help. I will always pray for you because I was living the most difficult days of my life from anxiety, depression, crying and sleep deprivation. When I talked to you, my life changed, rather it was complete, and I had hope! Young person*





## Youth Mentorship/Mentee Program

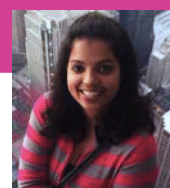
In partnership with the HDSA, the mentorship program is designed to support young people across the United States who face the everyday challenges of growing up in a family affected by HD. This program provides youth (mentee) with one-on-one time with another person (mentor) who will receive training, and ongoing support from a Youth Social Worker within the HDSA. We are actively accepting applications for mentors and mentees to expand this program future after our pilot.

In Partnership With



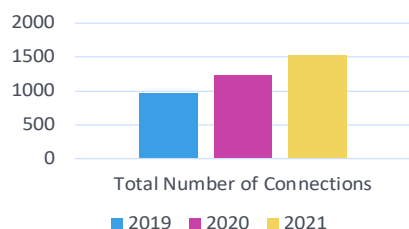
*Being a basic science HD researcher with some clinical experience, helped me understand the background of the disease and the impact it can have on thousands of HD families. HDYO and the mentorship program motivates me to help people who are in need associated with HD.*

Bhairavi  
Mentor - Michigan

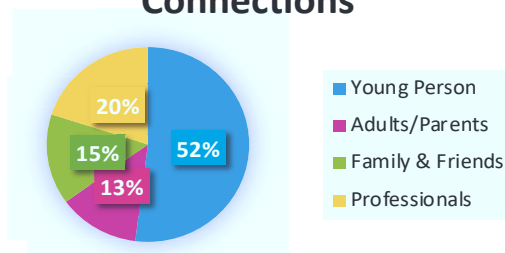


## HDYO Impact By the Numbers

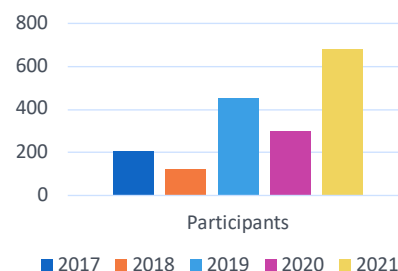
Website, Email &  
Program Connections



Connections



Event Participation





# Educate

HDYO strives to educate and provide resources for the community to support them through every part of their journey with Huntington's Disease. In addition to the robust content on HDYO.org, a series of programs have been developed to bring important topics and concerns directly to young people.



## Breaking Down Barriers Series

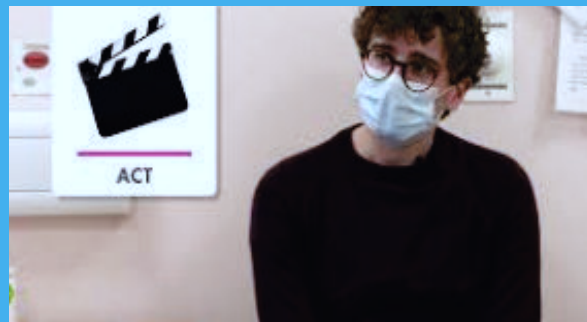
HD is a complicated disease. We aim to provide educational resources in an easy-to-understand format. We also help young people make connections and communicate with others about their experiences to help others. Breaking Down Barriers was designed to tackle these roadblocks to arm young people and families with this information to help them throughout their journey.

**Next Up in 2022...**Talking to Children about HD, Access to Health & Research, Being a Young Caregiver, Behind the Scenes Laboratory Tour, Speaking to Children About HD.

### An Insight Into Clinical Trials & Drug Development



### Participating in Clinical Research



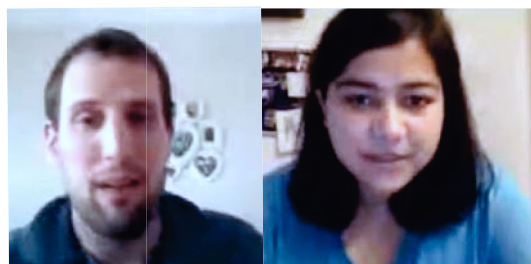
**Genentech**  
A Member of the Roche Group

Sponsored By  
**uniQure**

**Sage**  
Therapeutics®

## Matt's Chats

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





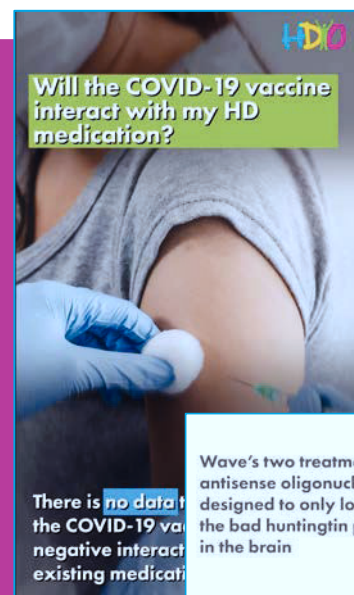


## Research Video Series

Let's face it...most people, especially young people, increasingly look to social media to get their news and updates. HDYO wanted to share the latest about HD research in a format that allows people of all ages to easily access on social media.

HD Buzz creates regular text updates of the latest HD research and has been a major assistance for the HD community. HDYO partnered with HD Buzz to use their research articles and to transform them into two minute-long videos that automatically play on social feeds without needing to click anywhere.

Launched in mid-summer, this series has been well-received with more than 1,000 views and 6 videos produced. We will continue to produce monthly videos on a variety of topics essential to the HD community. Look for more videos throughout 2022!



Wave's two treatments are both antisense oligonucleotides (ASOs), designed to only lower the bad huntingtin protein in the brain



by targeting spelling mistakes that are commonly found in the bad huntingtin gene

**Special thanks to our sponsors!**

**Genentech**  
A Member of the Roche Group



**Special thanks to our partner!**







## International Young Adult Congress

The HD community is incredibly diverse. There are vast discrepancies with the level and access of care, support and resources that are available, depending on your country and culture. HDYO has the unique ability to help young people across the world impacted by HD. We aimed to do that physically with our event in 2020. After re-imagining the original event to become virtual, HDYO hosted the first International Congress in March 2021.



This was the **FIRST** event of its kind because it brought together the HD community across the world in one place, virtually. Attendees heard from different research partners, learned from people in the community, got moving with yoga, dance and exercises, connected with others and walked away feeling inspired. All sessions are featured on YouTube for anyone to access at any time. This essential program was completely free for the community thanks to the generosity of our amazing sponsors. Feedback from young people in addition to pharmaceutical sponsors was extremely positive and 98% of respondents to our survey were excited to join another virtual congress in the next year.

### 2021 Congress By the Numbers

**1,700**  
BOOTH VISITS


**600+**  
YOUNG PEOPLE & FAMILIES

**OVER 29 COUNTRIES**

**3,000**  
SESSION VISITS

**30+**  
SPEAKERS


#### SOCIAL MEDIA PRESENCE

 +12,600 FOLLOWERS

 +1,600 FOLLOWERS

 +2,100 FOLLOWERS

 6,000 SUBSCRIBERS  
2.6 MILLION VIEWS

 2,000 SUBSCRIBERS



# Empower

At HDYO, our aim is to ensure all young people impacted by HD are empowered to help themselves and their families. We encourage them to be their own advocates by sharing their stories and connecting with others in the community.

Clare raised funds by running a half marathon.





## HDYO Ambassadors

Our Ambassadors are a group of young people from across the world who are leaders and advocates in the HD community and can help us extend our reach being boots locally on the ground. This group volunteers, raises awareness of HD, advises and fundraises for HDYO. They are truly global coming from US, Canada, South America, Europe, Australia and the Middle East. This group launched after the success of congress in 2021 and meet monthly. They share their experiences and aim to connect the HD community to show they are not alone. They provide support to community members throughout the year including sharing Top Tips to help others, outlining their own journeys, and more. They also keep their fingers on the pulse of the latest in HD and the impacts on young people.

### Meet Some of Our Ambassadors!

*Some Ambassadors Not Photographed*



**Ana**

Portugal



**Angela**

Australia



**Anne**

Columbia and Sweden



**Ashley**

Northern Ireland



**Shairavi**

US



**Brittany**

US



**Bruce**

Scotland



**Bruna**

Brazil



**Caitlin**

Canada



**Carly**

Wales



**Charlie**

England



**Claudia**

Italy



**Crystal**

US



**Emma**

Latvia



**Jamie**

England



**Jordan**

Scotland



**Lindsay**

Canada



**Lorena and Nelson**

Chile



**Niamh**

Ireland



**Sadie**

Canada



**Sarah**

US



**Tatiana**

Brazil



**Tess**

Sweden



**Zoe**

Scotland



## Huntington's Disease Community Advisory Board (HD-CAB)

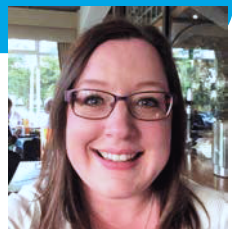
The European Huntington Association (EHA), the International Huntington Association (IHA) and the Huntington's Disease Youth Organization (HDYO) officially launched their new project, HD-CAB. As a coalition of partners, their mission is to represent the voice of the global HD community and provide HD community experience to regulators, industry, researchers and governing bodies.

HD-CAB is an instrument to facilitate patient-oriented research and clinical trials as well as fair processes to make treatment accessible for all patients. For HDYO it's so important to have the young persons voice heard as clinical trials look at early symptomatic and pre-symptomatic patients.



*We believe that Patient-oriented input is highly needed to meet the needs of the patient community, speed up recruitment and increase retention for all HD clinical trials. We hope that HD-CAB will be successful in incorporating the patient-voice in therapeutic development efforts in Huntington's disease.*

Hayley Hubberstey,  
HDYO Chair and Member of HD-CAB  
Management Team



### Partnered Organizations







## New Ways of Engagement

There are countless ways to give back and make your voice heard and represented in the HD community. HDYO has enhanced the various ways to give back to HDYO and to the community. These tactics will help diversify our methods of support while enhancing our mission.

### Ways to Give

**Personal Donations!** Supporters can give monthly or monthly and can choose to donate in honor of a loved one.

**Donate in Lieu of Gifts!** For the next celebration or in memory of a loved one, people can make a donation and choose to send a gift receipt to a loved one.

**Start a Facebook Fundraiser!** This is the perfect way to celebrate a birthday or milestone while giving back!

**Host Your Own Fundraiser!** From bake sales to bowling nights, to online parties and quizzes, there are many fun ways to gather to have fun and support HDYO.

**Participate on Behalf of HDYO!** Make HDYO the beneficiary for your next marathon or competition!

**Get Your Workplace Involved!** Whether you're an employee or an employer, we'd be happy to chat about making HDYO an approved charity for your workplace giving programs. There are three main ways for employers to support nonprofits: payroll deductions, grant opportunities and matching gifts.

**Make HDYO Your Beneficiary!** From 401ks to IRAs and other investment accounts, you can make HDYO your beneficiary.



**Henley Mermaids Fundraiser**

**Become A Sponsor** Your foundation or company can sponsor our programs that impact the lives of young people and families in the HD community globally. We also offer unique and custom sponsorship opportunities that allow companies and organizations to share their products and services, reach thousands of individuals and enhance their presence in the HD community.

**Volunteer!** From becoming an Ambassador to joining one of our committees, YOU can help so many others who have been impacted by this disease.



The HDYO team made great strides in our global Juvenile-onset HD Global Registry. This registry hopes to connect this under-served community and gather history to help support and direct future research for Juvenile onset Huntington's Disease.

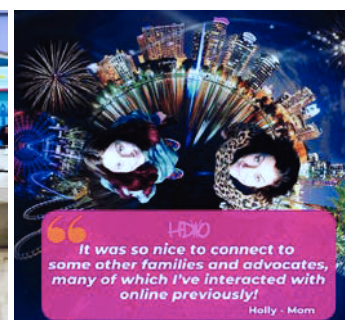
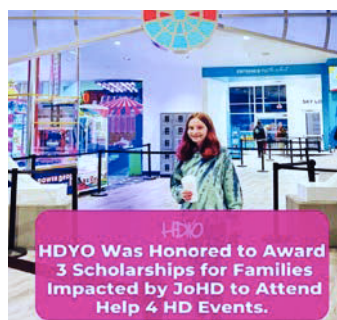
## 2021 Highlights

- Hired Dr. Rebecca Mason, a dedicated part-time coordinator to manage the registry
- Convened the Scientific Oversight Committee
- Formed the Family Advisory Council
- Pre-registered 32 families in 10 countries
- Presented posters and sessions at 4 conferences to share data and information including HDS Family Day, EHDN, Help 4 HD and Congress.
- Finalized Participant Experience
- Created study documents
- Enhanced registry portal
- Funded 3 families to attend Help 4 HD Conference

### Presented At:



### Awarded Scholarships:





## HDYO Team:      Scientific Oversight Committee



**Lauren Byrne**  
JOIN-HD Chief  
Investigator



**Bonnie Hennig-Trestman**  
HDYO research  
co-chair



**Rebecca Mason**  
JOIN-HD  
coordinator



**Martha Nance**



**Jean-Marc Burgunder**



**Oliver  
Quarrell**



**Leon Dure**



**Helen  
Santini**



**Benjamin Wilfond**

## What's Next?

The registry will open and active recruitment will begin in the first months of 2022. Any family who has been impacted by juvenile-onset HD is encouraged to register to help connect the community together, identify unmet needs and gaps in care, and to help speed up research for this important community. Once registered, participants will go through a screening call with Dr. Mason and then will receive log in information to complete a series of questionnaires. For more questions and information, email [registry@hdyo.org](mailto:registry@hdyo.org).



**Pre-Register Today!**

**Special thanks to our sponsors!**

**uniQure**





# FINANCIALS

## INCOME

Donations	£	16,996.06	\$	23,829.66
Grants	£	130,514.18	\$	179,530.25
	£	<b>147,510.24</b>	\$	<b>203,359.91</b>

## EXPENDITURE

Grants to HDYO UK	£	92,509.16	\$	125,000.00
Salaries	£	34,832.98	\$	47,919.73
Payroll costs	£	242.57	\$	333.70
Storage	£	112.05	\$	154.15
Postage & stationery	£	172.13	\$	236.80
IT costs	£	562.17	\$	773.38
Telephone	£	171.94	\$	236.54
Insurance	£	728.63	\$	1,002.38
Bank charges	£	125.78	\$	173.04
Office costs	£	599.17	\$	824.28
Accounts	£	1,987.43	\$	2,750.00
		<b>£ 132,044.01</b>		<b>\$ 179,403.99</b>
Surplus for Year		<b>£ 15,466.23</b>		<b>\$ 23,955.92</b>

Reserves B/F	\$	236,886.04
Surplus	\$	23,955.92
Reserves C/F	\$	<b>260,841.96</b>
<b>REPRESENTED BY :ASSETS</b>		
Checking Bank Account	\$	260,341.96
Stocks	\$	500.00



# THE TEAM

## HDYO Staff



**Jenna**  
Executive Director  
jenna@hdyo.org



**Jen**  
Mentorship Project  
Coordinator  
jen@hdyo.org



**Rebecca**  
JOIN-HD Study  
Coordinator  
rebecca@hdyo.org



**Matt**  
Founder & Project  
Coordinator  
matt@hdyo.org

## HDYO Board

### Executive Committee



**Hayley**  
Works in HD 2 yrs



**Rudolf**  
Works in HD 12 yrs



**Eric**  
Works in HD 11 yrs

### Education Committee



**Donna**  
HD Family Member  
Works in HD 10



**Heather**  
HD Family Member  
Works in HD 4



**Ashley**  
HD Family Member  
Works in HD 13

### Marketing Committee



**Clare**  
HD Family Member  
Works in Marketing 20



**Jenny**  
Works in Pharma

### Research Committee



**Bonnie**  
Works in HD 20



**Lauren**  
HD Family Member  
Works in HD 5

## Research Volunteer Committee

### Misty Daniel

Certified Clinical Research Coordinator,  
Scripps Health

### Dr. Beth Ann Griffin

Senior Statistician, RAND Center for Causal  
Inference

### Mustafa Mehkary

PhD Student, University of Toronto

### Marina Papoutsis

Biomarker Scientist, IXICO plc, Honorary  
senior research fellow, UCL

## Marketing Volunteer Committee

### Emily Hadley

Retail Buyer, World of Sweets

## Education Volunteer Committee

### Angela Abell

HDYO Ambassador, Impacted by HD

### Erika Brockhoff

Prenatal Genetic Counselor, Impacted by HD

### Marc Osborn

High School Teacher, Impacted by HD

### Bhairavi Srinageshwar

Post-Doc Research Associate

### Brittany Stowers

Student Studying Neuroscience and  
Psychology, Impacted by HD

### Dr. Emma Yhnell

HD Researcher, Cardiff University

### Jessi Way

Masters of Science, Licensed Professional  
Counselor, Impacted by HD



**HUNTINGTON'S DISEASE  
YOUTH ORGANIZATION**

**Join the Celebration in  
2022!**



@HDYouthOrg



@HDYOFeed



@HDYOFeed



@HDYO



@HDYOFeed



HDYO.ORG

Charity Registration No. 1145781

Company Registration No. 07821651 (England and Wales)

**HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD**  
**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2021**



**McLintocks**

Xeinadin Group

# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

## LEGAL AND ADMINISTRATIVE INFORMATION

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<b>Trustees</b>	C Braithwaite L Brynne H Ging B L Hennig-Trestman Dr H E Hubberstey C Martin U McNamara E Miller R Schaffrath D Spencer A Weiser
<b>Secretary</b>	Mr M J Ellison
<b>Charity number</b>	1145781
<b>Company number</b>	07821651
<b>Registered office</b>	28 Millais Close Bedworth Warwickshire CV12 8TH
<b>Independent examiner</b>	Helen Furlong FCCA McLintocks (NW) Limited 46 Hamilton Square Birkenhead Wirral Merseyside CH41 5AR

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# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

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# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

**FOR THE YEAR ENDED 31 DECEMBER 2021**

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The trustees present their annual report and financial statements for the year ended 31 December 2021.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's Memorandum and Articles of Association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019).

### **Objectives and activities**

The charity's objects are to relieve the need of young people impacted by Huntington's Disease in particular, but not exclusively, by the provision of information and support.

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

### **Achievements and performance**

During the year to 31 December 2021 the organisation launched the new redesigned website and entered into the following Educational programmes:

- 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 & encouraging future research
- Youth Mentorship Program. This program provides a young person (mentee) with one to one time with another person (mentor) who will receive training & 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.

### **Financial review**

In the year to 31 December 2021 the charity had incoming resources of £104,120 (2020 £202,043) and expenditure of £85,466 (2020 £205,855) giving a surplus of £18,654. Accumulated unrestricted free reserves at 31 December 2021 amounted to £42,683.

It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level equivalent to between three and six month's expenditure. The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has been maintained throughout the year.

### **Structure, governance and management**

The charity is a company limited by guarantee and is governed by the Memorandum and Articles of Association.

# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

**FOR THE YEAR ENDED 31 DECEMBER 2021**

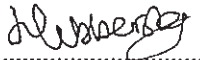
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The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

C Braithwaite  
L Brynne  
H Ging  
B L Hennig-Trestman  
Dr H E Hubberstey  
C Martin  
U McNamara  
E Miller  
R Schaffrath  
D Spencer  
A Weiser

None of the trustees has any beneficial interest in the company. All of the trustees are members of the company and guarantee to contribute £10 in the event of a winding up.

The trustees' report was approved by the Board of Trustees.



.....  
Dr H E Hubberstey  
**Trustee**

07/10/22  
Date: .....

# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

## INDEPENDENT EXAMINER'S REPORT

### TO THE TRUSTEES OF HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

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I report to the trustees on my examination of the financial statements of Huntington's Disease Youth Organisation Ltd (the charity) for the year ended 31 December 2021.

#### **Responsibilities and basis of report**

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 (the 2006 Act).

Having satisfied myself that the financial statements of the charity are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's financial statements carried out under section 145 of the Charities Act 2011 (the 2011 Act). In carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

#### **Independent examiner's statement**

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4 the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.



**Helen Furlong FCCA**  
**McLintocks (NW) Limited**

46 Hamilton Square  
Birkenhead  
Wirral  
Merseyside  
CH41 5AR

Dated: 12.10.22

# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 DECEMBER 2021

		Unrestricted funds 2021 £	Unrestricted funds 2020 £
	Notes		
<b><u>Income from:</u></b>			
Donations and legacies	3	13,458	7,448
Charitable activities	4	90,606	188,457
Other trading activities	5	56	6,138
<b>Total income</b>		<u>104,120</u>	<u>202,043</u>
<b><u>Expenditure on:</u></b>			
Charitable activities	6	<u>85,466</u>	<u>205,855</u>
<b>Net income/(expenditure) for the year/ Net movement in funds</b>		18,654	(3,812)
Fund balances at 1 January 2021		<u>24,029</u>	<u>27,841</u>
<b>Fund balances at 31 December 2021</b>		<u><u>42,683</u></u>	<u><u>24,029</u></u>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.



# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

## BALANCE SHEET

AS AT 31 DECEMBER 2021

	Notes	2021 £	£	2020 £	£
<b>Current assets</b>					
Cash at bank and in hand		43,883		25,229	
<b>Creditors: amounts falling due within one year</b>	<b>10</b>	<u>(1,200)</u>		<u>(1,200)</u>	
Net current assets			<u>42,683</u>		<u>24,029</u>
<b>Income funds</b>					
Unrestricted funds			<u>42,683</u>		<u>24,029</u>
			<u>42,683</u>		<u>24,029</u>

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 December 2021.

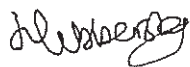
The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

07/10/22

The financial statements were approved by the Trustees on .....



.....  
Dr H E Hubberstey  
Trustee

Company registration number 07821651

# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

## NOTES TO THE FINANCIAL STATEMENTS

*FOR THE YEAR ENDED 31 DECEMBER 2021*

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### 1 Accounting policies

#### Charity information

Huntington's Disease Youth Organisation Ltd is a private company limited by guarantee incorporated in England and Wales. The registered office is 28 Millais Close, Bedworth, Warwickshire, CV12 8TH.

#### 1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's [governing document], the Companies Act 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" ("FRS 102") and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

#### 1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

#### 1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

#### 1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2021

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### 1 Accounting policies

(Continued)

#### 1.5 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

#### 1.6 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

##### **Basic financial assets**

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

##### **Basic financial liabilities**

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

##### **Derecognition of financial liabilities**

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

#### 1.7 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

#### 1.8 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2021

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### 2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

### 3 Donations and legacies

	Unrestricted funds	Unrestricted funds
	2021	2020
	£	£
Donations and gifts	<u>13,458</u>	<u>7,448</u>

### 4 Charitable activities

	2021	2020
	£	£
Grants received	<u>90,606</u>	<u>188,457</u>

### 5 Other trading activities

	Unrestricted funds	Unrestricted funds
	2021	2020
	£	£
Events	<u>56</u>	<u>6,138</u>



# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2021

### 6 Charitable activities

	2021 £	2020 £
Mentorship project costs	3,122	-
Research video costs	4,963	-
	<u>8,085</u>	<u>-</u>
Share of support costs (see note 7)	76,181	204,655
Share of governance costs (see note 7)	1,200	1,200
	<u>85,466</u>	<u>205,855</u>

### 7 Support costs

	Support costs £	Governance costs £	2021 Support costs £	Governance costs £	2020 £
Staff costs	47,785	-	47,785	87,860	87,860
Conference costs	10,966	-	10,966	67,912	67,912
Website costs	10,139	-	10,139	21,086	21,086
IT costs	1,967	-	1,967	2,311	2,311
Travel and accommodation	531	-	531	2,298	2,298
Printing, postage and stationery	1,673	-	1,673	1,069	1,069
Advertising	673	-	673	82	82
Professional fees	1,460	-	1,460	19,197	19,197
Administration expenses	884	-	884	2,825	2,825
Bank charges	103	-	103	15	15
Independent examination fees	-	1,200	1,200	-	1,200
	<u>76,181</u>	<u>1,200</u>	<u>77,381</u>	<u>204,655</u>	<u>205,855</u>
Analysed between Charitable activities	<u>76,181</u>	<u>1,200</u>	<u>77,381</u>	<u>204,655</u>	<u>205,855</u>

### 8 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

# HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2021

### 9 Employees

The average monthly number of employees during the year was:

	2021 Number	2020 Number
	2	2
<b>Employment costs</b>	<b>2021</b>	<b>2020</b>
	£	£
Wages and salaries	47,223	77,171
Other pension costs	562	10,689
	47,785	87,860

There were no employees whose annual remuneration was more than £60,000.

### 10 Creditors: amounts falling due within one year

	2021 £	2020 £
Accruals and deferred income	1,200	1,200

### 11 Related party transactions

There were no disclosable related party transactions during the year (2020 - none).

