

HDYO 2022 Year End Report



SUPPORT, EDUCATE, EMPOWER



A Letter from HDYO

Dear HDYO Community,

As we prepare to say goodbye to 2022, we hope this letter finds you healthy, safe and happy. Each year, we take time to reflect on the impact that HDYO has on the thousands of young people and families we help. While the year's stories are not quite completed, **we are excited to highlight some of our truly impactful successes and updates.**

We saw a shift in 2022 as the world transitioned back to in-person events. Nothing can replace the warm embraces and connections you get to make while seeing someone face to face. That did, however, encourage us to propel our in-person programs forward at a rapid pace while still serving the community through our unique programs.

2022 Impact Highlights

- Hosted our second International Young Adult Virtual Congress (483 participants)
- Expanded our Ambassadors of young people impacted by HD (62 Ambassadors)
- Solidified and enhanced partnerships with associations around the globe (20+)
- Released monthly Research Video Series in partnership with HD Buzz (11)
- Produced two new videos for Breaking Down Barriers and expanded to include casual conversations on social media
- Launched Stage 1 of JOIN-HD Global Registry
- Matched mentors and mentees together as a part of the Mentorship Program
- Co-Led 5 advisory board meetings as a part of HD-CAB
- Represented our community in several presentations across the globe
- **Continue to support young people through direct contact (impact numbers to be presented in January)**
- Welcomed new board members

One of the major highlights was the development of our **Five Year Strategy** that shows the path forward for HDYO and how we can partner and collaborate with the global community.

As you read through this report, we hope that you feel the optimism and passion that the Huntington's Disease Youth Organization has brought to our community. This is only possible with the tireless efforts of our team, and through the generosity of our volunteers and donors.

Thank you for your continued support to allow us to support, educate and empower young people impacted by HD.

Hayley Hubberstey, HDYO Chair



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In Their Own Words

I started crying and crying until I became severely depressed. I didn't talk to anyone. My depression lasted for two months. I decided to send my story to HDYO. This was the best decision I made in my life. It changed my whole life. They told me not to be afraid and that they would help me find a doctor. They sent me the name of a doctor from Egypt. My thinking changed radically after I got to know HDYO and my thinking became positive about the disease."

Young Adult, Iraq

A life with HD has been incredibly tough to accept. Things have definitely been hard, and I don't think I could have gotten to where I am today without the support of HDYO. I am so incredibly grateful for always being there if I need anything and for connecting me with so many other young people and a team of ambassadors who can truly understand everything a life impacted by HD brings.

Young Adult, Wales

I'm so glad for the outreach. It's hard adjusting to so many things. I never knew. Jenna is very sweet and kind. I think a lot about all that she and HDYO has done so far to help me. Such an amazing resource in my life.

Young Adult, US

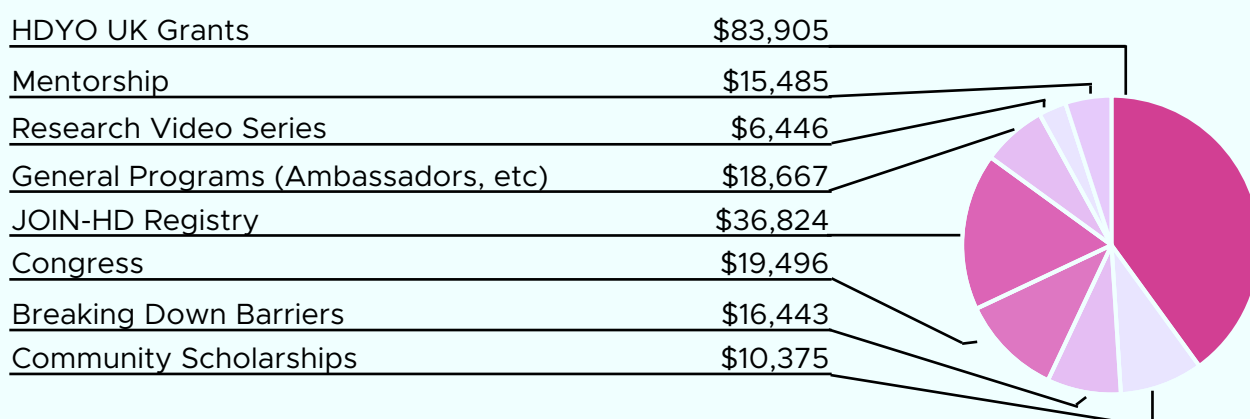
HDYO has been a really positive experience and resource in my life. After getting in contact with them during Congress in 2022, everyone has been so welcoming and nice. They also have been there for me when I was down.

Young Adult, Scotland



2022 Financials & Impact

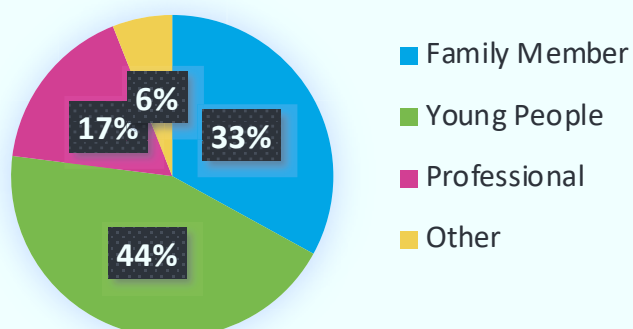
Total Income	\$375,270
Total General & Administrative Expenses	\$73,9391
Total Fundraising Expenses	\$61,105
Total Expenses Dedicated to Programs	\$212,537



By the Numbers

As we moved into a full two years of virtual support and educational programs, we found that our impact and reach extended well beyond what has been traditionally known as key HDYO programs. We have seen our programs live on past inception dates to truly make an impact in the HD community across the globe.

Types of Contacts



Outreach and Participants

	2021	2022
Registered Congress Participants	685	465
Post Congress Participants (YouTube)	6862	7309
Online Educational Programs	16,928	46,551
Total Participants	24,471	54,325



HDYO Marketing Stats

This report details the main marketing presence. We are in the process of building up our LinkedIn and TikTok presence.

Twitter

- Audience – Mainly scientific and professional
- 1.2K daily impressions
- 110K total impressions in 2022
- 6.2% increased engagement in 2022
- Most popular posts – research-based

Instagram

- Audience – Young People
 - Top Countries - 40% US, 21% UK
 - Ages: 30% 25-34; 25% 35-44; 13% 18-24 & 45-54
- 48,600 Reach – 435% Increase
- 7,000 Profile Visits – 65% Increase
- Average Post Reach – 275

Facebook

- Audience – Young People
 - Top Countries - 31% US, 15% UK, 12%
 - Ages: 36% 25-34; 21% 35-44; 16% 45-54
- 60,000 Page Reaches
- 76% Increase of Page Visits
- 12% Increase of Page Likes

Email

- Total Email recipients - 79,000 (49,000 in 2021)
- Avg. Open Rate – 35.4% (2021 – 21%; Non-profit Avg – 25%)
- Avg. Click Rate/Email – 6.5% (2021 – 3%; Non-Profit Avg – 6%)





Mentorship Program

Partnership With



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.

2022 Highlights

In-Person Training

- Hosted training in Charlotte, North Carolina in October
- Brought back Mentors who were previously trained virtually and new mentors

Recruitment

- Exhibited at HDSA Convention, Vanderbilt Symposium, and Help4HD Symposium
- Presented program at NYA Day
- Postcards sent to chapters to recruit during their events
- Increased social media presence

Mentor Demographics

- Trained Mentors: 13 Mentors; Ages: 17-30; New Applications - 4
- All but one come from a family in which a parent has been diagnosed with HD
- One has a sibling diagnosed with JHD in addition to a parent with HD
- Variety of testing status and experiences (at risk, gene positive, gene negative)
- One mentor does not come from a family affected by HD but has a background in Neuroscience and has been an HD researcher for several years in a hospital setting bringing different perspectives and experience to the group

Mentees

- Paired Mentees: 4; Mentees to be paired: 4; Mentees to be interviewed: 1





Breaking Down Barriers

Breaking Down Barriers

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.

HDYO continued this program with 2 more produced videos and the launch of our casual conversations around different barriers and stigmas.

- Participating in Research – We followed and documented two young people as they participated in Enroll-HD in England.
- Behind the Scenes Lab Tour – We followed a young person behind the scenes of a lab doing pre-clinical research to humanize the process and connect the scientific and advocacy communities. This was filmed in Michigan.
- Observational Studies – We hosted a conversation online with notable researchers and professionals who are instrumental in studies. That included Ed Wild, Jamie Levey, Jamie Hamilton, Karen Anderson, Shari Kinel and Lauren Byrne.

Watch Videos

Breaking Down Barriers: Observational Studies

Tuesday, December 6 - Facebook & YouTube



Jamie Levey
Enroll-HD

Dr. Karen Anderson
Georgetown University

Shari Kinel
HSG

Dr. Lauren Byrne
UCL

Dr. Ed Wild
UCL

Dr. Jamie Hamilton
CHDI



Sponsored By:



Future Projects Depending on Funding

- Access to Trials
- Speaking to Children about HD
- What is Gene Therapy
- Clinical Trial Myths – Delivery Methods
- Questions to Ask Your Doctor
- Quality Time with Symptomatic Loved Ones

Special thanks to our sponsors!







Research Video Series

2022 has been a pivotal year for HD research with some highs and definite lows. This series continues to be one of the more popular resources we provide not only to educate but to also provide the hope through different research accomplishments. Our aim is to do monthly videos, but this is dependent on the different articles and topics published through HDBuzz. So far in 2022, we have created 10 videos with the 11th in production currently.

Watch Videos



 hdyofeed ...

 hdyofeed HDYO Research Video Series: novartis Update with New Oral Therapy for HD


In partnership with #HDBuzz, we are excited for our next HDYO Research Series Video. Branaplam was originally designed to treat spinal muscular atrophy, but a new paper outlines how it could hold promise for treating Huntington's. This oral drug lowers huntingtin protein and will now be tested in a study called VIBRANT-HD.

Thanks to our sponsors, #uniQure, #Neurocrine Biosciences, @sagebiotech, and #teva.


For translated subtitles, visit the Research Video Series YouTube Playlist link in bio.

#research #clinicaltrial #raredisease #huntingtonsdisease #letstalkabouthd #novartis

27w

 veronicazavel_art 🙏🙏🙏🙏🙏🙏

27w 1 like Reply

 argenis_gotera_hd hello. I'm Argenis from Venezuela, Kat and Matt know me...thanks for this beautiful video 😊 Is there a possibility that this video will also be published in

Boost post

Special thanks to our sponsors!

uniQure

NEUROCRINE
BIOSCIENCES

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Therapeutics®

teva

Special thanks to our partner!

HD
BUZZ



Virtual Congress

This year's virtual HDYO Congress was a huge success! While our numbers were slightly lower than in 2021, we had a wider variety of attendees from more countries, and roughly half of the attendees had not participated in the 2021 event. We have also had continual views of our sessions and use these as an educational tools for our programs. These videos are also available in closed captioning in multiple languages. We improved the participant experience with chat rooms, social media wall, contests and more.

Watch Sessions

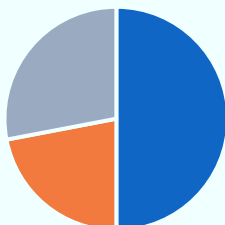
Self-Identified Attendees

- 483 Registered
- 40 Countries Represented

Overall

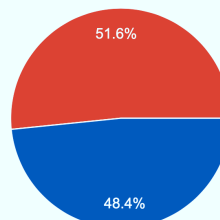
- 1,300 session visits during the event.
- 5,317 total session views via YouTube (as of December 19)
- 650 booth visits

Participants

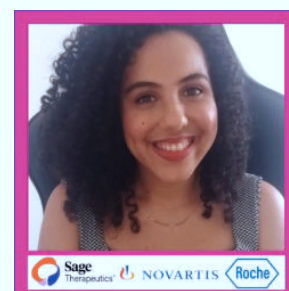
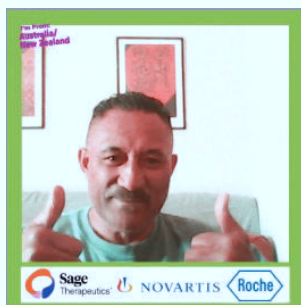
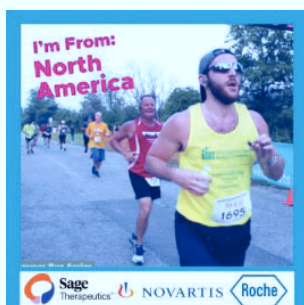


■ Family ■ Professional ■ Young Person

Did you attend Congress in 2021?
31 responses



● Yes
● No



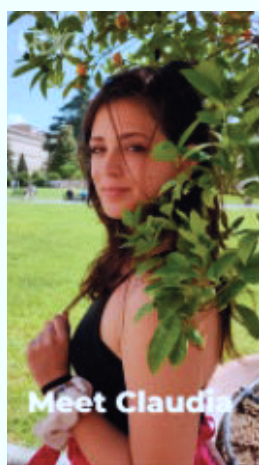


Ambassadors

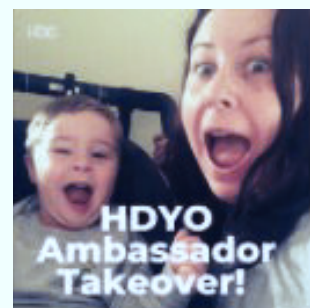
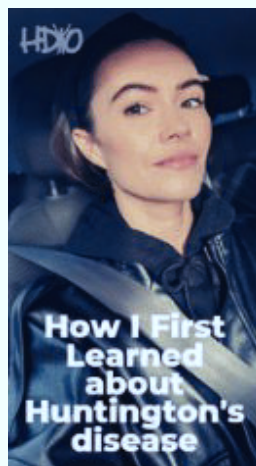
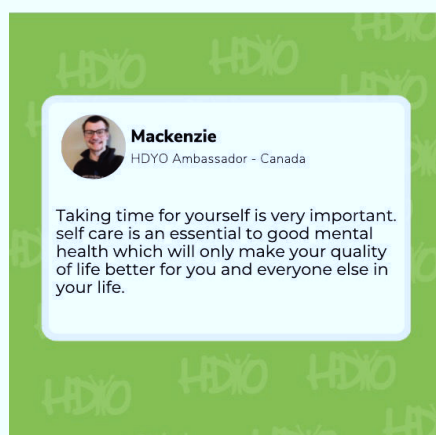
Our Ambassadors celebrated their first full year in May. During that monthly meeting, notable community members shared their gratitude. That included Charles Sabine, Dr. Bonnie, Astri Arnesen (EHA), Seth Rotberg, BJ Viau and Jimmy Pollard. Several associations have expressed their want to partner and develop similar programs. Pharmaceutical companies have used their experiences to help educate their internal teams.

2022 Highlights

- Have reached a milestone of more than **60 Ambassadors in 18 countries**
- Hosted monthly meetings
- Introduced them into helping with HDYO programs
- Expanded ambassadors from the US
- Created a training program to increase their knowledge and confidence being leaders in the community
- Shared 12 months of top tips, the most impactful being about symptom searching
- Hosted 10 social media take overs in the month of May to increase awareness. Each story was told in their own languages through videos and posts. Topics included: How did they find out about HD, How has HD impacted relationships, How do they cope, How have they become involved in the community, etc.
- Hosted 5 social media takeovers in July for Rare Revolution Magazine
- Selected some ambassadors to serve as peer supporters on the HDYO Facebook Hangout Support Group
- Ambassadors presented at EHDN during HDYO's sessions
- Prilenia featured some ambassadors in their May awareness campaign
- Secured a dedicated sponsorship from Teva



Meet Claudia



Special thanks to our sponsors!

uniQure

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teva



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 HD-CAB in September 2021. As a coalition of partners, this group's 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 person's voice heard as clinical trials look at early symptomatic and also pre-symptomatic patients.

In its first year, HD-CAB Boasts:

1. Recruited 26 members in 20 countries offering diverse relationships to HD
2. Provided training and education to advocates
3. Hosted two virtual (Novartis & PTC) and three in-person Advisory Boards (PTC, uniQure and Annexon)
4. Pushed industry to consider the global perspective and community access concerns
5. Partnered with HSG to help facilitate Annexon advisory board meeting

"I have been involved in the planning of many advisory board meetings. It's an important endeavor, but it's always a lot of work. Through their proactive approach, HD-CAB made it much easier. They helped us understand how important it is to work together and inspired us to keep moving forward. We at uniQure came away with invaluable insights and got the chance to share more of our work with the community we're working for."

Daniel Leonard
uniQure



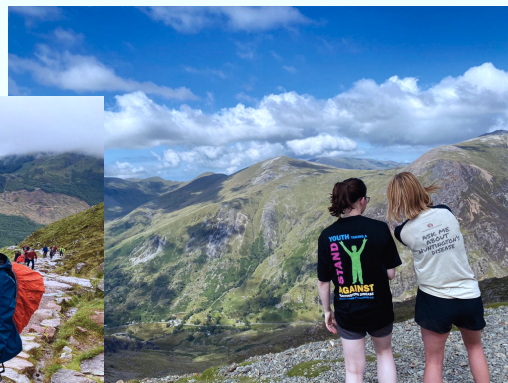
Partnered Organizations





Fundraisers

**3 Peaks Challenge
Raised ~£4,000**



**Grandpa Stamps
Holiday Cards
Raises ~\$600 annually**



**Jenna Runs a 10K
Raised \$4,000**

**Mt. Kilimanjaro Climbs
February 2023**

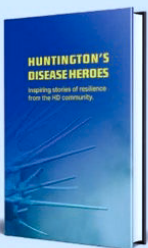




HD Heroes

Huntington's Disease Heroes Anthology

THIS BOOK WILL:



Give a voice to the Huntington's community

Control the narrative of our experiences

Help people who are going through similar things

Take the fear & stigma away from living with a rare disease

Connect us as a community and show us we are not alone

 @LEMONADEPRESSBOOKS

- Collection of 20+ community stories from across the globe.
- Will be published in early 2022.
- Forward is written by Charles Sabine.
- 50% of proceeds will be donated to HDYO.
- Charles will do book signing at Congress.
- HDYO has a chapter that Jenna wrote.
- Many Ambassadors are featured.

Introducing an HD Hero

"HDYO is approached by young people across the globe about their challenges & worries about HD. There were several instances where people have never met anyone else who has even heard of HD, let alone understands how it feels to be impacted."

 Lemonade Press




Jenna, Executive Director of HDYO, USA

Writer Spotlight

Huntington's Disease does not define you, it is a small part of your DNA. We still have a chance to live an amazing life even with HD.

ASHLEY - AT RISK FOR HD, UK
#HDSHERO



 Lemonade Press



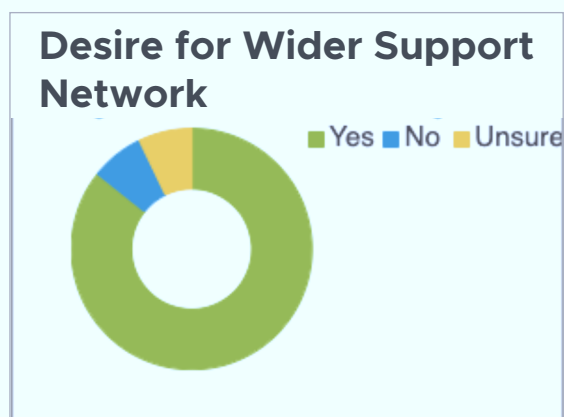
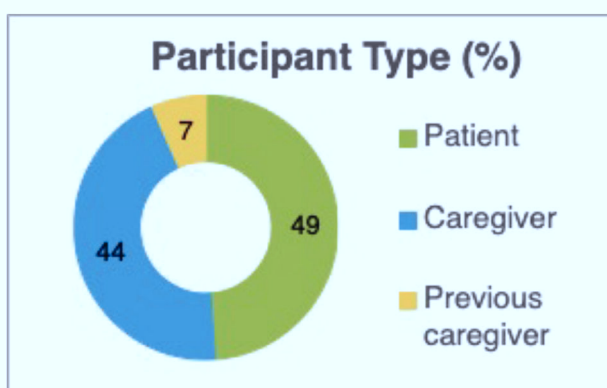
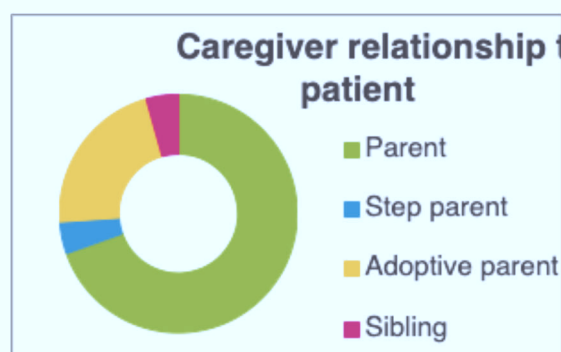
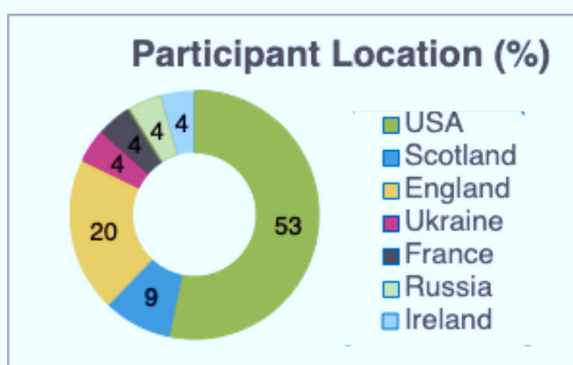
JOIN-HD Global Registry



2022 Highlights

- Officially launched Stage 1 in February 2022
- 69 families pre-registered
- 45 fully enrolled
- Presented posters and sessions at several conferences globally: HSG, EHDN, HD SA, CHDI, Congress, HDA JHD Weekend, ECRD, Hereditary Disease Foundation, UK HD Network Meeting
- Developed family advisory board
- Launching new platform for Stage 2
- Created Social Media JOIN-HD support page
- Added new members to Scientific Oversight Committee
- Launched JOIN-HD.org

Current Data





JOIN-HD Global Registry

HDYO Team:



Lauren Byrne
JOIN-HD Chief
Investigator



Bonnie Hennig-Trestman
HDYO Research
Co-Chair



Jenna Heilman
HDYO Executive
Director



Kelly Atkins
HDYO Research
Co-Chair



Lauren Youngborg
HDYO Education
Co-Chair



Martha Nance



Jean-Marc Burgunder



Oliver Quarrell



Leon Dure



Helen Santini



Benjamin Wilfond



Peg Nopoulos



Ferdinando Squitieri

Special thanks to our sponsors!

uniQure



NOVARTIS



In-Person Representation Snapshot





Looking Ahead to 2023

First In-Person HDYO International Congress

Planning is well underway for the first ever in-person Congress held in Glasgow, Scotland. Scholarship recipients from 2020 are carried over to this event, and we are currently finalizing sponsors, logistics, and activities. Highlights include Enroll-HD hosting a celebration event the Saturday of Congress for their 10-year anniversary.



HDYO Congress

STRIVE – Supporting and TRaining International Voices to Excel

As the dedicated advocate for young people impacted by HD, we have a responsibility to champion support needed for professionals helping youth and young people across the globe. This network would pool resources & provide support (not financially) for the international programs. That includes:

- Convening professionals for peer support
- Providing Continuing Education
- Developing a Database of Service Providers
- Organizing a library of materials & resources
- Encouraging global collaborations

Survey Series

The need and manner in which the HD community searches for & receives resources has been greatly impacted by the pandemic. In addition, there is a lot that we need to further understand for how HD impacts a young person's journey throughout the major milestones in their life. We will be implementing a series of surveys to help in certain key areas & we are currently finalizing our IRB approval and hope to start dissemination in February and at Congress. This information will be published to train professionals on effective outreach methods.

Camps

The flagship program of HDYO has been camps. We will aim to host camps every other year in a different country starting in North America in 2024. Planning has already begun for this event and will continue full-speed in 2023.

Next Steps:

- *Engage and collaborate with local associations*
- *Logistics*
- *Create planning committees to help with organization*



HDYO Team

Staff

Our dedicated staff is made of passionate individuals who are here to support you. Please feel free to reach out to us directly.

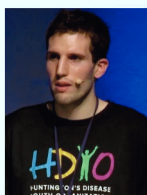


Jenna Heilman

jenna@hdyo.org

Executive Director

Full-Time



Matt Ellison

matt@hdyo.org

Project Coordinator and
Founder

Impacted by HD

8 Hours/Week



Jenna Shea

jen@hdyo.org

Project Coordinator -
Mentorship

Impacted by HD

4 Hours/Week

Board

Executive Committee



Hayley Hubberstey

hayley@hdyo.org

Chair



Trey Randall

trey@hdyo.org

Secretary



Jarrod (Jay) Strydo

jay@hdyo.org

Treasurer

Research Committee



Dr. Bonnie Hennig-Trestman

DrBonnie@hdyo.org

Co-Chair Research
Committee



Dr. Kelly Atkins

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Co-Chair Research
Committee



Dr. Lauren Byrne

lauren@hdyo.org

Chief Investigator - JOIN-HD
Registry
Impacted by HD

Education & Advocacy Committee



Lauren Youngborg

lauren.youngborg@hdyo.org

Co-Chair



Ashley Clarke

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Co-Chair

Impacted by HD



Seth Rotberg

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Chair

Impacted by HD

Marketing & Fundraising Committee



Matthew Shore

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Co-Chair

Impacted by HD



Clare Braithwaite

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Co-Chair

Impacted by HD



Jenny Harte

jenny@hdyo.org

Board Member

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

Bhairavi Srinageshwar

Post-Doc Research Associate

Education Volunteer Committee

Erika Brockhoff

Prenatal Genetic Counselor, Impacted by HD

Bhairavi Srinageshwar

Post-Doc Research Associate

Brittany Stowers

Neuroscience and Psychology, Impacted by HD

Dr. Emma Yhnell

HD Researcher, Cardiff University

Jessi Way

Licensed Professional Counselor, Impacted by HD

Wes Solem

Genetic Counselor, HD Genetics

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 2022



McLintocks

Xeinadin Group

HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	C Braithwaite	
	L Byrne	
	B L Hennig-Trestman	
	Dr H E Hubberstey	
	A Clarke	
	J Harte	
	K Atkins	(Appointed 17 August 2022)
	J Strydom	(Appointed 27 July 2022)
	T Randall	(Appointed 27 July 2022)
	L Youngborg	(Appointed 27 July 2022)
	M Shore	(Appointed 27 July 2022)
Secretary	Mr M J Ellison	
Charity number	1145781	
Company number	07821651	
Registered office	28 Millais Close Bedworth Warwickshire CV12 8TH	
Independent examiner	Helen Furlong FCCA McLintocks (NW) Limited 46 Hamilton Square Birkenhead Wirral Merseyside CH41 5AR	

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 2022

The trustees present their annual report and financial statements for the year ended 31 December 2022.

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 2022 the organisation continued with 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.
- Young Adult Virtual Congress - This was held in March 2022 and had 483 participants globally.

Financial review

In the year to 31 December 2022 the charity had incoming resources of £83,097 (2021 £104,120) and expenditure of £75,809 (2021 £85,466) giving a surplus of £7,288 (2021 £18,654). Accumulated unrestricted free reserves at 31 December 2022 amounted to £49,971.

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 2022

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 Byrne

B L Hennig-Trestman

Dr H E Hubberstey

E Miller

(Resigned 30 September 2022)

R Schaffrath

(Resigned 30 October 2022)

D Spencer

(Resigned 30 December 2022)

A Clarke

J Harte

K Atkins

(Appointed 17 August 2022)

J Strydom

(Appointed 27 July 2022)

T Randall

(Appointed 27 July 2022)

L Youngborg

(Appointed 27 July 2022)

M Shore

(Appointed 27 July 2022)

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

26/9/23

Date:

HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

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 2022.

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:

HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 DECEMBER 2022

		Unrestricted funds 2022 £	Unrestricted funds 2021 £
	Notes		
<u>Income from:</u>			
Donations and legacies	3	19,442	13,458
Charitable activities	4	63,655	90,606
Other trading activities	5	-	56
Total income		83,097	104,120
<u>Expenditure on:</u>			
Charitable activities	6	75,809	85,466
Net income for the year/ Net movement in funds		7,288	18,654
Fund balances at 1 January 2022		42,683	24,029
Fund balances at 31 December 2022		49,971	42,683

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 2022

	Notes	2022 £	£	2021 £	£
Current assets					
Debtors	11	7,086		-	
Cash at bank and in hand		44,085		43,883	
		<u>51,171</u>		<u>43,883</u>	
Creditors: amounts falling due within one year	12	(1,200)		(1,200)	
Net current assets			49,971		42,683
Income funds					
Unrestricted funds			49,971		42,683
			<u>49,971</u>		<u>42,683</u>

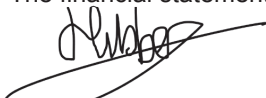
The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 December 2022.

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.

The financial statements were approved by the Trustees on26/9/23..


.....
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 2022

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 2022

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.

1.7 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

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.

HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2022

1 Accounting policies

(Continued)

1.8 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.

1.9 Retirement benefits

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

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
	2022	2021
	£	£
Donations and gifts	19,442	13,458

4 Charitable activities

	2022	2021
	£	£
Grants received	63,655	90,606

HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2022

5 Other trading activities

	Total Unrestricted funds	
	2022 £	2021 £
Events	-	56

6 Charitable activities

	2022 £	2021 £
Mentorship project costs	1,116	3,122
Research video costs	3,785	4,963
JOIN - HD costs	127	-
Breaking Down Barriers costs	2,830	-
Virtual Congress costs	11,023	-
	18,881	8,085
Share of support costs (see note 7)	55,728	76,181
Share of governance costs (see note 7)	1,200	1,200
	75,809	85,466

HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2022

7 Support costs

	Support costs	Governance costs	2022 Support costs	Governance costs	2021
	£	£	£	£	£
Staff costs	31,436	-	31,436	47,785	47,785
Conference costs	-	-	-	10,966	10,966
Website costs	8,760	-	8,760	10,139	10,139
IT costs	3,302	-	3,302	1,967	1,967
Travel and accommodation	-	-	-	531	531
Printing, postage and stationery	186	-	186	1,673	1,673
Advertising	618	-	618	673	673
Professional fees	6,234	-	6,234	1,460	1,460
Administration expenses	531	-	531	884	884
Bank charges	279	-	279	103	103
Accountancy and payroll costs	4,382	-	4,382	-	-
Independent examination fees	-	1,200	1,200	-	1,200
	<u>55,728</u>	<u>1,200</u>	<u>56,928</u>	<u>76,181</u>	<u>77,381</u>
Analysed between Charitable activities	<u>55,728</u>	<u>1,200</u>	<u>56,928</u>	<u>76,181</u>	<u>77,381</u>

8 Trustees

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

9 Employees

The average monthly number of employees during the year was:

	2022 Number	2021 Number
	<u>2</u>	<u>2</u>
Employment costs	2022 £	2021 £
Wages and salaries	31,246	47,223
Other pension costs	190	562
	<u>31,436</u>	<u>47,785</u>

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

HUNTINGTON'S DISEASE YOUTH ORGANISATION LTD

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2022

10 Taxation

The charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

11 Debtors

	2022 £	2021 £
Amounts falling due within one year:		
Other debtors	6,598	-
Prepayments and accrued income	488	-
	<u>7,086</u>	<u>-</u>

12 Creditors: amounts falling due within one year

	2022 £	2021 £
Accruals and deferred income	1,200	1,200
	<u>1,200</u>	<u>1,200</u>

13 Related party transactions

There were no disclosable related party transactions during the year (2021 - none).