HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

HDYO 2021
Mid Year Report
July 2021

SUPPORT, EDUCATE, EMPOWER

2021 Mid Year Report

The first half of 2021 has been nothing short of transformational in our efforts to support youth and families with HD. While this year has introduced additional challenges, it also has brought new opportunities to serve this important community. We've delivered an amazing amount of new projects, expanded our staff and hosted our first Virtual Congress.

Our Staff

Welcome to our new staff members!

- Jenna Heilman Executive Director (US, start date August 2, full time)
- Jenna Shea Project Coordinator (Canada, start June, 4 hours/week)
- Rebecca Mason JOIN HD Study Coordinator, Juvenile Onset Huntington's Disease Registry, (UK, start date April, 3 days/week)
- We also still have our Founder & Project Coordinator Matt Ellison (UK, 4 days a week)

Jenna Heilman: Executive Director Introduction:

For 15 years, I have enjoyed leadership roles in both non-profit & for profit sectors, developing a reputation for strategic thinking & planning. I quickly found out that my heart belongs to non-profit life. I recently left the Executive Director position at the Head for the Cure Foundation. Their mission is to build awareness, raise funds & ignite hope for the brain tumor community. When I started in 2017, HFTC had hit a plateau for fundraising & with the staff.

Over that tenure:

- We restructured the foundation to allow for maximum growth.
- Re-tooled the financial reporting to allow for more grant opportunities.
- Doubled the dollars raised from $1.6 to $3 million annually between 2017 & 2019.
- Developed our marketing platforms, including new websites & social media presence.
- Created new programs to provide education & support to patients & caregivers of all ages.
- Started a national podcast to bring awareness to brain cancer
- Lifted HFTC's reputation internationally as a force within the advocacy community.

I truly believe that the best way to make an impact is through developing each relationship to truly understand how we can make a difference together. I'm so honored to join the amazing team as the Executive Director at HDYO. I have an unwavering passion to help all who have faced the most difficult of challenges to bring hope and inspiration throughout their journey.

Jenna Shea, Project Coordinator North America, Introduction:

Jenna, a teacher, is a mother to two little girls and a member of a family deeply affected by Huntington's Disease. Over the last several years, Jenna has taken on role as a patient advocate for those affected by HD. She is currently a mentor for the Youth Mentorship Program through the Huntington Society of Canada (HSC) and has supported HSC's efforts to raise awareness by sharing her story of HD. In 2018, Jenna became a member of HD-COPE, a coalition for patient engagement that seeks to incorporate the patient-voice in global therapeutic development efforts for HD. Since joining HD-COPE, she has shared the experiences those affected by HD with regulators, researchers and industry professionals through her role on various advisory boards. In 2018, Jenna was presented with the "Change-Makers Award" by the Neurological Health Charities of Canada for the care she provides to her mother who lives with HD.

Prior to her involvement with HD, Jenna worked with Canada's leading national youth organization as a project support leader. During her role with that organization, she supported young people from various backgrounds. She is excited to work with HDYO as the Project Coordinator for the Mentorship Program. Growing up in a family affected by HD, Jenna understands that isolation and lack of peer understanding can present challenges for young people affected by HD and knows the value and importance of the support of positive role models.

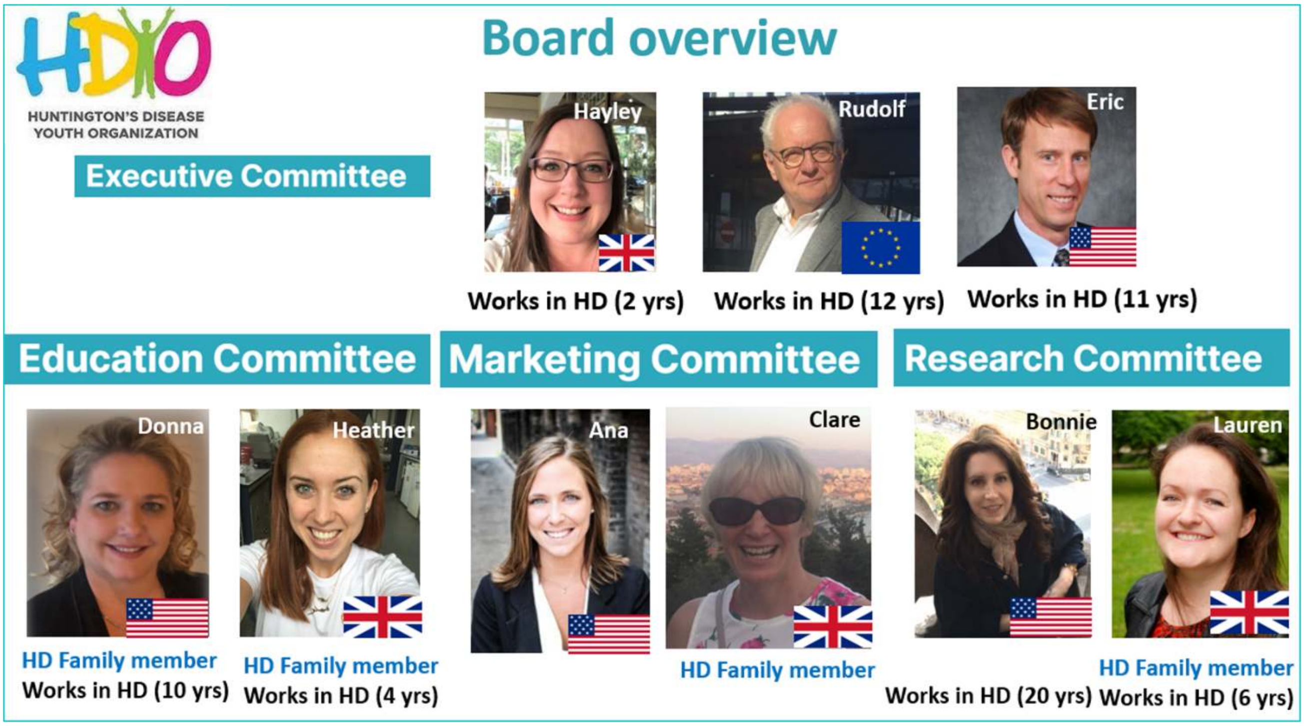
Rebecca Mason, JOIN HD study coordinator, Introduction:

I'm Rebecca, I live in Sheffield in the UK. My educational background is in biology, with an undergraduate degree in Human Biology and a PhD in Biochemistry. My PhD research was on the topic of Parkinson's disease.

I started working in clinical research after completing my PhD, joining the Sheffield Children's Hospital research team in 2017. In this role my time was split between managing a portfolio of paediatric rare genetic disease studies and working on adult HD studies. Working on paediatric studies gave me experience working with young people and their families in a research setting, something I enjoyed greatly. In terms of HD research, I first worked on the observational Enroll-HD study before moving on to coordinating the GENERATION-HD1 drug trial in 2019. Working with HD families and within the HD research community was a great experience and something I was keen to continue.

I joined HDYO in April 2021 as Study Coordinator for the JOIN-HD Registry study, allowing me to continue working on HD research and combining it with working with young people. I am thrilled to be working on this project as research into JoHD has been limited by its rarity, and a global patient registry like JOIN-HD has the potential to help

The Board



HUNTINGTON'S DISEASE YOUTH ORGANIZATION

Board overview

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 yrs)

Heather
HD Family member
Works in HD (4 yrs)

Marketing Committee

Ana

Clare
HD Family member

Research Committee

Bonnie
Works in HD (20 yrs)

Lauren
HD Family member
Works in HD (6 yrs)

Our talented and dedicated board remains as passionate as ever about the future of HDYO. They have continued to move the organization forward to strategize, strengthen and accelerate the direct impact to young people with in the HD community. With hopes of adding new board members throughout the rest of 2021, these leaders are instrumental in this organization.

The Board lead the volunteer committees for their area of expertise too.

2021 Headlines – It's Been a Busy Year So Far!

Frontline and Staying Connected - an increase in contacts.

Virtual Congress - was a huge success with 640 registered attendees catch up here: https://hdyocongress2021.vfairs.com/ and our You tube channel

JoHD Registry - Family database to build more understanding for the community working with the wider community

Mentorship Project - Mentorship program for young people from HD families, peer to peer support working with HSC and HDSA

Launch of the HDYO Ambassadors - replacing the Young Leaders Network

Education projects - Research updates in a short video format, working with HD Buzz.

Rebrand - new branding rolling out across all materials.

Global Huntington's Disease Community Advisory Board (HD-CAB) - replacing the previous partnership.

Frontline & Staying Connected – Jan to June 2021 In Numbers

With virtual congress getting **over 600** registrants our contacts list for this year is incredibly high in comparison to any other year. We have **1240 contacts** so far this year, and our highest yearly total was last year with 1230. We have already passed our record for most contacts in one year, and we have half the year to go.

By June 30 we have had:

- ✓ 41 new Donations
- ✓ 47 Requests
- ✓ 90 Support/Questions
- ✓ 175 responses to Surveys
- ✓ 669 attendees to Virtual Congress
- ✓ 126 Webinar attendees
- ✓ 38 attendees to our Staying Connected monthly social calls

Frontline & Staying Connected – Jan to June 2021 In Numbers

Youth Support

We reach out to young people constantly by a mixture of social media and direct contact. Our aim is to reassure and support.

Staying Connected Monthly Support Groups

We have continued our topical monthly support sessions, known as Staying Connected, which give young people a chance to share with their peers and HDYO staff and have had 38 participants over our first 5 sessions this year.

Matts Chats

Our monthly video interview series, Matts Chats, has featured 4 videos this year so far, with another coming out very soon, and we have had 600 views on Youtube.

Each of these videos has been watched by more than 200 of our young people.

Mental health: https://www.youtube.com/watch?v=A861WZdxBBA

At risk of HD: https://www.youtube.com/watch?v=4D0JkAuuZiI

HD documentary https://www.youtube.com/watch?v=LzTP69uQH8A&t=7s

Webinar IVF experiences: https://www.youtube.com/watch?v=0sNkSn1CyQ0 100 people watched

Webinars response to Roche and Wave news:

In response to the Roche and Wave research news all the organizations came together to support the community, with HDYO holding 3 webinars in total following this news and a third more recently after people had had some more time to process.

https://www.youtube.com/watch?v=PsSjTPgxwAQ&t=1413s, 100 live attendees and 350 people post event.

Virtual Congress

HDYO's Virtual congress in March was a huge success. Covid haulted our in person congress in May 2020, but the virtual event hosted more than 600 participants from 48 countries. The global representation of our attendees was really strong. With our original participation goal of 200-300 attendees, it's safe to say that this program exceeded all expectations.

The event itself was excellent with 2 days of 35 sessions with 2 tracks to choose from each day. There was an enormous amount of quality content to choose from as an attendee. Our content was watched over 3000 times live and a further 3000 times on YouTube since the event. The virtual aspect of the event went seamlessly with a team working to ensure everything was working exactly to schedule over both days.

In addition to the program success, we also received donations totalling $1000 from attendees who valued the free event and wanted to say thank you.

Virtual Congress Feedback

“Amazing conference, very full of high-quality content - really enjoyed it!” – Young person, England

“Amazing, so well organised slick and just unbelievable to do what you did given the challenges.” – Young person, Scotland

“The event was an interesting experience that allowed many cultures to come together and share their stories and experiences on this common topic of concern. I really enjoyed the event and have never been to anything like it.” – Young person, Venezuela

“Just wanted to drop you a quick note after yesterday. I hope you're still on a high from a really successful conference! It was very well managed and went super smoothly from all the sessions I saw. And a huge congratulations for doubling your initial predictions of registrations Matt! 600 is super impressive.

Whilst I wasn't the primary audience of course, I came away feeling incredibly energised. The speakers were all really fantastic, vulnerable yet empowering. And given the last year we have had, it was great to have this as a lift for the community.

Finally, thank you for having us participate in the session yesterday - I really hope the audience found it useful. If you do have any feedback either from yourselves or from the audience then please do let me know so we can improve for next time.”

Many thanks

“Congratulations, a fantastic conference so inspiring….. roll on day 2.” Roche

“Congratulations to you and the rest of the team on a successful conference! I hope everything went well on your end.

I wanted to let you know that the Breaking Down Barriers initiative might be something that we could support.” Uniqure

JOIN-HD Juvenile Onset Huntington’s Disease Registry Launch

The Juvenile-Onset Initiative for Huntington's Disease

JOIN-HD is a global patient registry with the primary aim of identifying and locating young people impacted by Juvenile-onset HD (JoHD). The current plan is for JOIN-HD to include three stages. A summary of the three stages of JOIN-HD is summarized below.

Stages	Pre-enrolment	Stage I	Stage II	Stage III
Consent requirements	Tacit consent*	Data Consent*	Informed Consent*	Site-specific informed consent*
Assessments	Demographics*	Community	Experiences Medical History	Clinician-led Interviews Pedigree

JOIN-HD Stage Diagram

JOIN-HD Stage 1:

Eligibility to participate in JOIN-HD will be classified into two categories:

1.JoHD: the primary population consisting of individuals whose clinical symptoms are consistent with JoHD that manifested before their 21st birthday.

2.Caregivers: individuals who are significantly involved in caregiving of an individual with JoHD who can report on their clinical manifestations.

There are no restrictions on ethnicity or race. Individuals over the age of 18 will be invited to participate. Individuals under the age of 18 will invited to participate with parental/guardian approval.

Recruitment

HDYO will actively utilise our global network to recruit eligible participants.

These networks include: HD charities and family associations; professional networks such as EHDN and HSG; and a number of specialty or community clinics or physicians who work with people who have HD and JoHD.

In the past, HDYO has been successful in using social media and network platforms to reach families impacted by HD who are not currently engaged in mainstream organisations or clinics. Therefore, participants may also learn about JOIN-HD through websites, social media, advocacy newsletters, and support groups.

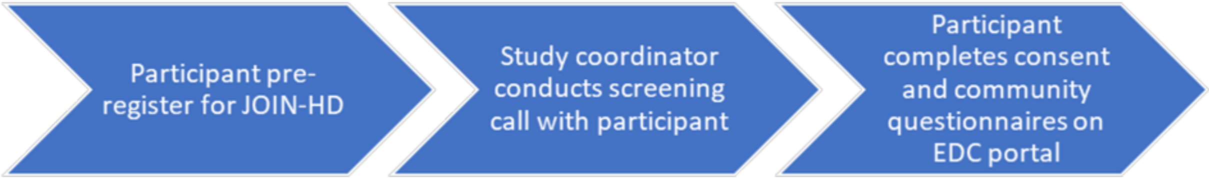
The JOIN-HD team also intends to harness the voices of trusted key advocacy leaders in the HD community to promote JOIN-HD. Additionally, the JOIN-HD team will perform snow-ball sampling where enrolled participants may refer other potential individuals for enrolment.

Potential participants will be referred to the JOIN-HD study coordinator and will be asked to pre-register their demographic information. Once participants pre-register, Participant Information Sheets will be sent and a video call with the JOIN-HD study coordinator will be arranged.

The study coordinator will explain the project in more detail and confirm eligibility. Eligible individuals will then be provided access to an electronic data capture (EDC) portal via email, permitting them to self-enrol onto the registry. When the participant logs into the EDC they will be asked to confirm consent and complete a community questionnaire about their current involvement in the HD community.

They will also be asked whether they wish to be contacted or gain further support from HDYO in the future as well as if they are willing to be contacted about future research initiatives.

This process is summarised below. All information entered into the JOIN-HD EDC will be anonymised to ensure that no individual participant is identifiable.



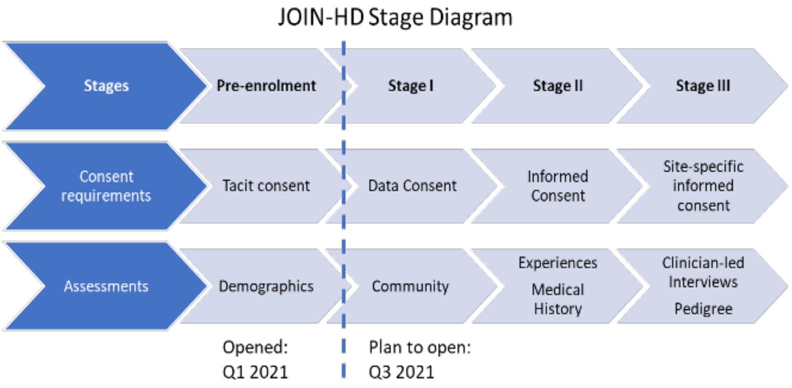
Summary of Pre-Registration and Stage I

Progress

A great deal of work has taken place on the registry platform and registration launched at the International Young Adult Congress in March 2021

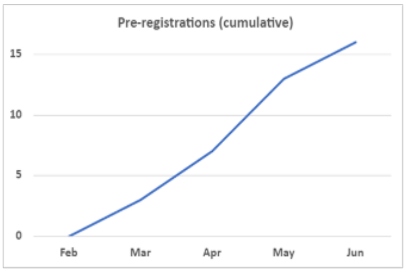
We are delighted to have opened the first ever global registry for families affected by JoHD. This will mean so much to the JoHD community due to the lack of knowledge and research into this rare condition.

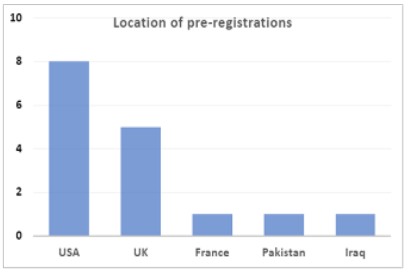
The information we collect will pave the way for improvements to advocacy, care and advancing trials in this area. A summary of the progress made so far in 2021 is shown below.



JOIN-HD Stage Diagram

Stages	**Pre-enrolment**	**Stage I**	**Stage II**	**Stage III**
Consent requirements	Tacit consent	Data Consent	Informed Consent	Site-specific informed consent
Assessments	Demographics	Community	Experiences Medical History	Clinician-led Interviews Pedigree
	Opened: Q1 2021	Plan to open: Q3 2021		





Progress made:

- ✓ Pre-registration opened March 2021
- ✓ Study coordinator started April 2021
- ✓ 16 pre-registrations from 5 countries
- ✓ Established a Scientific Oversight Committee

In progress:

- ➢ Increasing recruitment
- ➢ Securing further funding
- ➢ Getting the platform ready to open Stage I
- ➢ Creating study documents
- ➢ Establishing a family advisory group
- ➢ Gaining EHDN approval

Future plans:

- ➢ Obtain ethical approval for Stage II

Mentorship Project – In Partnership with HDSA

The Mentorship Program is designed to support young people facing the everyday challenges of growing up in a family affected by Huntington disease. HDYO in partnership with the Huntington Disease Society of America (HDSA) is committed to offering a mentoring program that provides young people with one-on-one time and attention with a mentor who will receive ongoing support from a qualified professional.

Goal Of The Program

Offer young people the opportunity to connect with a trained peer mentor who will be able to provide them with valuable support at critical points in their lives,

Assist young people in making informed decisions as well as prepare them for challenges they may encounter.

This program serves to help breakdown the sense of isolation many young people affected by HD experience by providing young people with positive role models and support system as well as connecting them to the wider HD community.

Looking Back

Working closely with the HSC), which has successfully implemented a Mentorship Program in Canada, we were able to "Train the Trainer".

In March, over the course of four days, the team responsible for supporting the Huntington Society of Canada Mentorship Program delivered a virtual training to the youth social workers with the Huntington Disease Society of America (HDSA) and HDYO Founder, Matt Ellison. The training covered the whole development process of the Mentorship Program from start to finish with advice from HSC staff who have spent years working on their own program. The training was given to relevant HDYO and HDSA staff to enable them to develop the same service in the US.

Moving Forward

Supported by the HSC, the HDSA has developed an online application. At this time, the application process is open and is now accepting applications for both mentors and mentees.

For the first round of training, the HDSA has opted for an "Invite to Apply" process for Mentors and will begin recruiting through HSDA's National Youth Alliance. HDYO and HDSA will continue to partner with HSC for the first round of training, to develop a training that mirrors what was delivered in the Canadian Mentorship Program.

Due to the current situation and ongoing restrictions posed by COVID-19, the first training in June 2021, will be a virtual training. It will include 6-7 mentors. We have opted for a smaller sized training to create more cohesion within the cohorts, especially since we won't be holding the trainings in person.

The training will cover the following topics: Roles and Responsibilities, Confidentiality and Social Media, Grief and Loss, Self-Disclosure and Setting Limits, Listening and Empathy, Mental Health and Suicide Awareness, and Self-Care. When we have finished the training, we will begin to match mentors and mentees based on needs, experience and compatibility.

We have opted to have a rolling application process to ensure that we have adequately recruited enough mentors and mentees for the second round of training currently scheduled to take place in October 2021.

We will share a further update in July following our first virtual training session.

Research Update

HDYO Board of Directors Research Committee has also been involved in the Mentorship Program. The focus of the committee is to create assessments for both mentors and mentees. These assessments will collect data at regularly scheduled intervals and will analyse the de-identified data to determine the following:

1) What are the needs of the community

2) If these needs are being met; and

3) The satisfaction of both mentors and mentees in the Mentorship Program.

The results of this data will guide future programming to ensure young people impacted by Huntington's Disease feel less isolated and supported.

The HDYO Ambassadors Launch

In April we launched our revamped young leaders network initiative HDYO Ambassadors. The aim is to engage people who want to volunteer, raise awareness of HD and fundraise for HDYO. Hayley leads this as a volunteer initiative with an awesome youth worker from Ireland.

In the 1st month, we had 40+ sign ups from across the globe.

Our youth HD social media community is truly global so having this representation from Canada, US, South America, Europe, Australia and the Middle east of young people is amazing.

We are sharing stories of HD online to spread awareness and support young people who want personal experience and advice and who want to be involved in fundraising campaigns later in the year.

We have a few older volunteers who have been through a lived experience of PGD IVF and their stories have been invaluable for our younger adults.

Awareness Month

Our HDYO Ambassadors shared their stories and experiences throughout May and June to help others not feel alone and provide reassurance:

Anne: https://en.hdyo.org/eve/blog/654

Erin's Story: https://en.hdyo.org/eve/blog/656

Emma's Story: https://en.hdyo.org/eve/blog/655

Tatiana's story: https://en.hdyo.org/eve/blog/658 https://www.youtube.com/watch?v=hrF_0dhvufA&t=88s with 300 views of her video

Angela's Story: https://en.hdyo.org/eve/blog/659

Our next activity is our Top Tips, by young people for young people. Each of our ambassadors contributes a "top tip" on subjects such as caregiving or self care and we combine into a clear social media image and this will help other young people giving them support and ideas for them to put into practice

Feedback From Our Ambassadors

“So much fun to feel part of something”

“So extremely cool to be online with people all across the world”

“Allowed me to gain knowledge and confidence and help me accept my test result. I feel like being part of this community will really help me and boost my self esteem. gain a lot of awareness for HD and will do everything I can to support.”

“Fantastic opportunity To raise awareness to HDYO and HD and help raise funds but also to meet people from all over the world and have fun.”

“I’ve been excited to learn more from other people, not only about their experience and HD information but how it’s different in every individual and every country. I’m really looking at gaining more connections within HD community but more importantly sharing awareness and helping in anyway I can.”

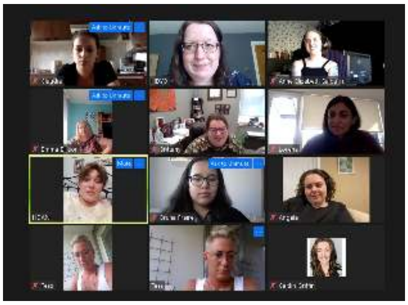
“I have a lot of stories to tell but also how to handle your mental health during those times.”

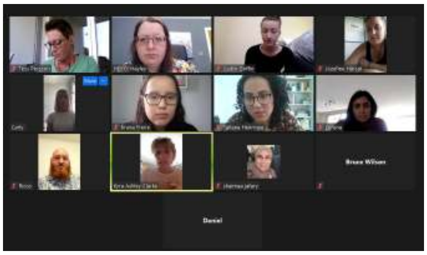
“I enjoy telling my story from a more positive perspective, inspiring the youth that there are good moments, and that we have to value those more than anything.”

“I’ve enjoyed meeting people in the HD community and spread the word about HD. There are so many people who don’t understand the disease or know about it.”

“Liked being involved in the HD community, with helping fundraise or outreach myself or helping others to perform outreach or fundraising. I'd like to continue this to a more international scale.”

“I’ve enjoyed helping others through genetic testing and family planning options like IVF-PGD. Sharing that there is more to life than HD. I was excited to meet new people from across the globe.”





Educational Projects

HDYO's Research Video Updates

The idea behind this project is to produce monthly video updates on the latest HD research news. HD Buzz creates regular text updates of the latest HD research and has been a major addition to the HD community, but we feel there are a range of people who won't read the articles HD Buzz writes but would watch a short video on the same topic.

That is what this project aims to do: take the latest HD news and put it into a short informative video update that people can view on their social media channels without needing to click anywhere. We hope this will bring the HD research news to a lot more people in our community.

Roche Video https://www.youtube.com/watch?v=xH0BzUIbmvk

Wave Video https://www.youtube.com/watch?v=-_RcqvD7GAw

Clinical Trial and Drug Development Video

As part of our breaking down barriers video series for this year we are creating an animated video that explains drug development and clinical trials in an easy manner. This video is being produced right now and should be ready in 2 months.

Young People's Experiences of Participating in HD Research Video

Another video project from our breaking down barriers series is focused on gathering the experiences of young adults participating in HD research. We aim to film this at UCL who are very happy to take part and we are now looking for the young participants. This one will be public in the 2nd half of 2021.

HDYO Rebrand

Background

The visual identity for HDYO had not changed since the charity was launched.

There was criticism that certain elements look too childish and there was a lack of consistency of branding on the different marketing materials.

The branding & messaging needs to work with a number of different audiences.

The Rebrand

An updated logo was developed. This is an evolution of the existing one but bringing it up to date with a bolder font and brighter colours.

The visual identity uses bright blocks of colour to stand out and photos of young people.

A style guide is being developed to ensure the branding has consistency in all our uses and those of our partners.

Old Logo

HDYO
HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

New Logo

HDYO
HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

HDYO Rebrand

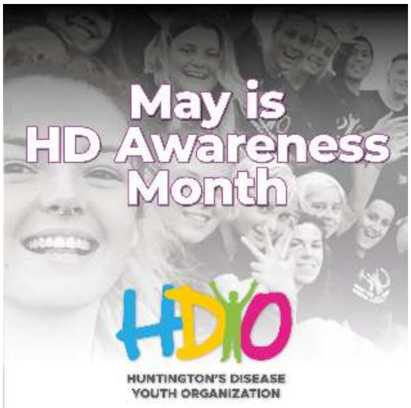
Stage 1: Launched on Social Media – May 2021

SUPPORT, EDUCATE, EMPOWER

What's our story?

The Huntington's Disease
Youth Organization

We are an international non-profit organisation supporting, educating and empowering young people, up to 35 years, impacted by Huntington's Disease around the world.



HDYO

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Visit en.hdyo.org

SUPPORT, EDUCATE, EMPOWER

Next Stages: Website and Marketing Materials

Global Huntington’s Disease Community Advisory Board (HD-CAB)

«The Huntington’s Disease Youth Organization (HDYO) is thrilled to join and be an equal partner in the HD-CAB coalition together with International Huntington Association (IHA) and the European Huntington Assocation (EHA),» says Hayley Hubberstey, chair of the HDYO board. «We look forward to working together to achieve HD-CABs mission and ensure that with this initiative we have a coordinated, and consistently knowledgeable mechanism, to contribute HD community experience including young people experience globally to regulators, industry and researchers,» Hayley continues.

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.

HD-CAB has a global perspective with members from 6 out of the 7 continents and the main aims are defined by the 3 partners, HDYO, EHA and IHA. The partners agree that HD-CAB should:

- Coordinate with pharmaceuticals with our global advisory team to ensure research progression is effective.
- Advocate with governing bodies globally to make drugs accessible to the HD community