

HDYO 2020 Report and 2021 Project Overview



HDYO Staff & Board

6/2/2021

Contents

HDYO 2020 Report and 2021 Project Overview	0
2020 Report	1
International Young Adult Congress May 2020	2
Virtual Congress March 2021.....	3
Staying Connected Project.....	4
Education Projects	4
Mentorship Project	6
Young Leaders Network.....	7
JoHD Registry	8
Key Numbers For 2020.....	10
2020 Finance overview	13
2021 Project overview and Request For Funding.....	14
2021 Finance overview	16

2020 Report

2020 was the most unpredictable and challenging year we've had to date due to Covid-19 sweeping across the world. This caused HDYO and many organisations to alter plans early 2020. We had to be flexible with that need to change from a packed calendar to lockdown support services.

HDYO adapted to 2020's challenges as well as we could. From the feedback we have received, we know we have continued to support young people well. In 2020 we had the largest number of people contacting us since 2012, in part due to our Covid-19 lockdown services, which engaged with a huge number of people during a stressful time.

We finished the year with the exciting news that HDYO's Founder and Project Coordinator, Matt Ellison, had been awarded an MBE (Member of the British Empire) by the Queen for his work at HDYO, which is a huge honour for him and fantastic recognition for HDYO that will help us moving forward into 2021 and beyond. More on MBEs here:

https://en.wikipedia.org/wiki/Order_of_the_British_Empire



We also expanded our volunteer board this year and are so pleased to have experienced professionals and HD family members making up our board.



Executive Committee

Board overview



Hayley

Works in HD (2 yrs)



Rudolf

Works in HD (12 yrs)



Eric

Works in HD (11 yrs)

Education Committee



Donna

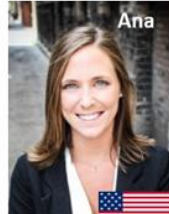
HD Family member
Works in HD (10 yrs)



Heather

HD Family member
Works in HD (4 yrs)

Marketing Committee



Ana

Works in marketing



Clare

HD Family member

Research Committee



Bonnie

Works in HD (20 yrs)



Lauren

Works in HD (6 yrs)

International Young Adult Congress May 2020

Firstly we must start with our event that wasn't able to take place due to Covid-19. Congress has been in the works for around 2 years and it was looking to be really a fantastic experience. Hundreds of young adults around the world were set to come to Glasgow either using their own budget or with the help of HDYO's scholarship fund. We had a full three day agenda of world class speakers all ready to go. In March when we had to postpone the event, we had 200 registrations. We expected to have 500 attendees at our first International Young Adult Congress, which would have been a wonderful achievement. Sadly, we had to postpone the event from May 2020 to March 2021.

It's a shame that the pandemic came at a terrible time for our Congress. We are not to be defeated and our aim is to hold 1-2 smaller in person events, once we're able to do so with the funding received. As an alternative, we have pivoted to hold our Congress virtually, taking place in March 2021.

Thank you to our sponsors and donors for your continued support in making our Congress a success, albeit virtually.



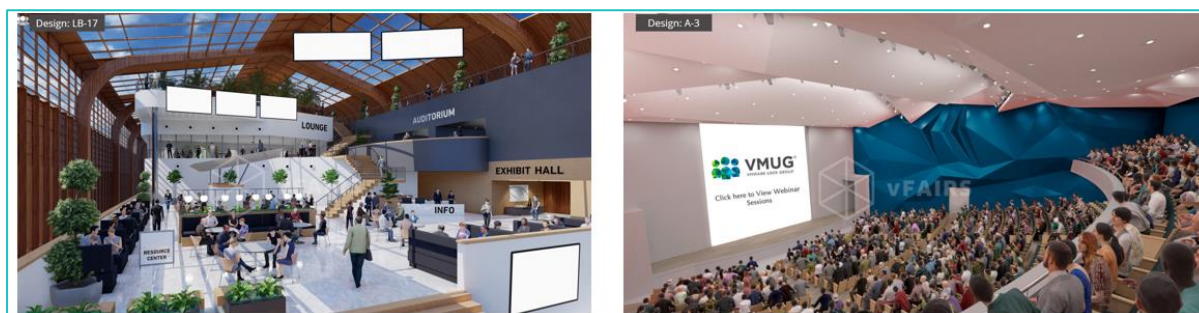
Virtual Congress March 2021

Following on from the news above, we recently announced that we will be holding a virtual Young Adult Congress in March 13-14 2021. This is a 2 day event for young people, families and professionals, and is free to attend. We already have 100+ people registered which is a very positive start. We are in the process of launching our agenda which is looking very strong with most Congress Speakers transferring over to the virtual event. To guarantee the delivery of a successful event we've hired a specialist virtual events company to work with us, which will be very beneficial to all attendees. The website to see the details is here:

<https://hdyocongress2021.vfairs.com/>



Sneak peak at our virtual auditorium for our amazing sessions:



Key numbers so far:

- 35 speakers (including 6 pharma companies)
- 33 sessions across 2 days
- 7 pharma companies will have booths to visit and provide information
- 100+ attendees and counting...

Our young people and the wider community are so excited for the virtual Congress:

"We are almost there, so excited" - Young adult, UK

".. we are all struck down with coronavirus but as horrible as it was, we avoided hospital, here's hoping 2021 will be a better year and cant wait for the Young Adult Congress!!!"- Parent, USA

Staying Connected Project

In April we created the Staying Connected Project as a response to the global lockdowns. It was about bringing young people together online in a facilitated format where they can share experiences on various topics using zoom calls. This was HDYO being flexible and adapting to what was happening to the world in 2020. We started by doing weekly support groups and some other activities such as yoga and game nights and have now reduced this to a monthly service with different topics each month.

This project has been a huge success with over 350 young people taking part across those 8 months of running the project. Our Yoga programme ran for 3 months and we also had 2,340 individual views of our videos (live and recordings afterwards). Young people have found it incredibly beneficial to talk to each other, especially during lockdowns. We also did some sessions in different languages with Italian being very popular. We intend to keep this project going into 2021 and we thank our donors for enabling us to deliver this in 2020 (Griffin Foundation, uniQure, PTC therapeutics, Roche, Sage, Wave, Takeda).

“Thank you for your time yesterday it was just what I needed to gain some confidence and feel not so alone” - Young adult, Canada

*“Really enjoyed the opportunity to do some yoga with fellow HD members yesterday!”
Young adult, USA*

“Thank you for the people HDYO has brought into my life”- Young Adult, USA



Education Projects

Website Redesign and Upgrades

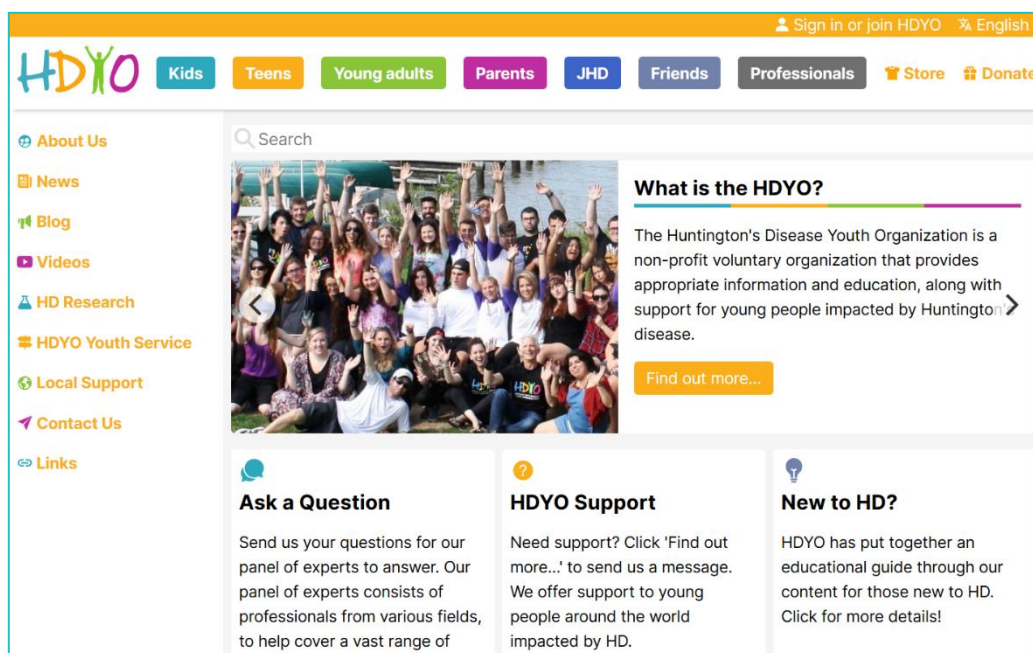
We have worked hard on a major update to the website this year making our site much more engaging and accessible with a fresh face. We redesigned our homepage, article format, video section and content management system (CMS) for the back end of the site. We've also added a new to HD guide to our homepage to help those who are coming to us with no information about HD so they can get started on their HD journey in the right manner. We have made some strong additions to the site.

It has been a big effort to get it done but most of the upgrades are now live, with one more small update set to take place in spring 2021. We have seen increases of 5.6% traffic, 9.2% time spent and 15.6 % page views since the changes were implemented. We are also setting up a feedback group of our users to get their honest feedback on the site improvements and ease of navigation around the site to the educational content.

Take a look for yourself: www.hdyo.org. So far we've had some great feedback:

"It looks great!" - Young adult, Venezuela

"Beautiful site, much better than a lot of other HD sites" - website survey feedback



Website: Bullying Section

We added a new article to our site for bullying as this is something that a lot of young people in HD families experience. This article acknowledges those challenges and provides hope and support for those young people dealing with bullying and HD.

You can see the bullying section here with feedback below:

<https://en.hdyo.org/tee/articles/599>

"As someone who has gone through bullying at school, I am so happy to see this covered by HDYO. thank you!" - Teen, England

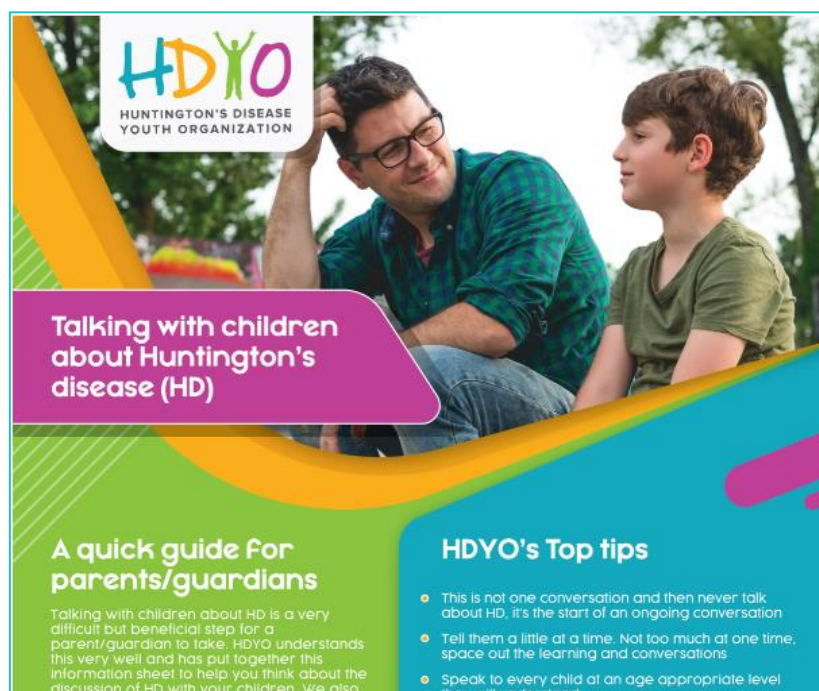
Matt's Chats Series

We also started a new show called Matt's Chats in which we interview people on certain topics. This started relatively recently with our first one about being 25% at risk going out in October. Our next session with Triplet Therapeutics went live in December. We're aiming to make this a successful series of video interviews that will go on social media and the website. This type of video conversation proves hugely popular with young people and is a great format to engage our target audience. We currently have 420 individual video views.

Talking With Children About HD Flyer

We have a lot of content in our parents section of the website on talking with children about HD. However following a number of questions in early 2020, we wanted to respond to this. We have put all the main points for our parents into a handy guide when talking to their children. We have also put together a 2 page flyer that parents can pick up from our booths (once we return to face-to-face events). It can also be downloaded from our site for parents/guardians or anyone to get what they need very quickly.

The flyer is also free to order from our store in downloadable format or paper version to be shipped: <https://en.hdyo.org/tee/store/18>



"Great looking flyer thank you!" - Parent, USA

Having Children: The Options Brochure

Our having children article on our site is one of the most comprehensive articles listing all the options available to those looking to have children, from a HD family. We also get so many questions about this, with young people reaching out for support. We are in the process of making this article into a short brochure to once again offer that at booths or as a downloadable PDF and provide that extra accessibility for people to view this important information. This brochure is not quite in store yet as it's in final draft but it will be available very soon.

Mentorship Project

HDYO's Mentor Project took its first strides this year and we aim to expand this further in 2021. The mentorship project (originally developed by the Huntington Society of Canada) is essentially a buddy system for young people and young adults to be paired as mentors and mentees to receive peer support in a controlled setting. HDYO intends to bring the Mentor Project across the globe in the coming years and this year we started with the US.

We are working very closely with the Huntington's Disease Society of America (HDSA) on this project and just held a training event for eight professionals from HDSA who will co-run the mentor project with us in the US. That training has been completed and in 2021 we will hold training for mentors and then mentees will be able to access the service in the US.

It's a project which has a lot of professional time and input in the background to make it run smoothly and as such, it takes time to put together. The US plan is going very well so far and will continue into 2021 where again we have funding to proceed with the project.

Thank you to Genentech and Neurocrine for funding for this project.



Young Leaders Network

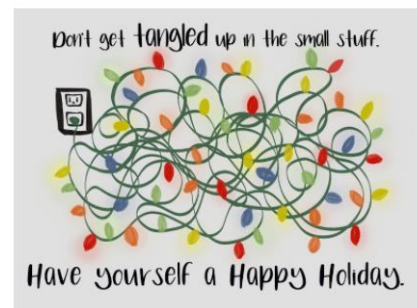
The idea behind the Young Leaders Project is to engage with young adults in the HD community. Through regional groups, young adults can join and meet others like them, as well as getting involved with HDYO activities. The service launched last year with some test groups in the US, but Covid-19 really impacted our ability to do in person community events where this project would thrive. We pivoted to online events with our Young Leader Captains. We had a successful (in terms of engagement and fundraising) 2020 holiday campaign. Young people from over 12 different countries designed 50+ cards and came together to celebrate what we are all thankful for despite these very difficult times.



HOME FOR CHRISTMAS



HDYO Holiday Cards – Alex's design
\$13.00



HDYO Holiday Cards – Gabbi's design
\$13.00

We also had our Young Leaders write some fantastic articles and blogs supporting our Top Tips Tuesday and Thankful Thursday initiatives. They shared their stories and in turn, helped young people find comfort in relatable stories.

See the links to these articles below and thank you to Teva for funding this project.



Thankful by Young person, USA: <https://en.hdyo.org/eve/news/647>

HDYO helps children and young adults know that there's nothing to be ashamed of. That they aren't alone in the world, that they're not destined for a life without joy, without hope. They bring community to people across the world who need it so desperately, now more than ever. I am so unbelievably thankful for the HDYO family, and everything they've done to keep this community together in the midst of this incredibly difficult year. I know budgets are tight this year, but I'm giving to HDYO for Giving Tuesday, and I hope you'll join me if you're able.

Positive Coping Strategies for Stressful Times by Jessi Voegtline, USA:
<https://en.hdyo.org/eve/news/648>

During this difficult time, it may be good to have a couple of positive coping strategies to get through the tough parts of the day. If you are feeling that you need more than these strategies, please seek professional help in your area or reach out to your local mental health centers and/or the suicide prevention number.

Surviving the holidays and change in season by Abi Kane, Young adult, USA:
<https://en.hdyo.org/eve/news/649>

I hope these few tips helps you navigate this insane year we are all witnessing. I know I am one among many when I say my inbox is always open to talk if you need someone to just listen or to offer you advice. Keep on Keepin' on Warriors!

JoHD Registry

At the start of 2020 HDYO moved forward with a very ambitious project to try and raise the bar for families impacted by Juvenile onset Huntington's Disease. Juvenile onset HD is onset of motor symptoms prior to a person's 21st birthday. Have a look at our article explaining it more [here](#). It is estimated that on average, 4.92% of all HD cases worldwide are JoHD.

Currently there are no treatments and no clinical trials targeting JoHD. It is a very different disease compared to adult-onset HD and there is a global lack of general knowledge about JoHD specifically. There are also a limited amount of healthcare providers, support, resources, or treatments available for those impacted by JoHD. According to a 2018 HDYO survey the JoHD community feels underappreciated and under supported. HDYO's mission is to help ALL young people impacted by HD. This includes young people with JoHD and their families.

To that end our ultimate goal of a JoHD registry is to:

- Improve advocacy, care and support for young people with JoHD and for their families.
- Create a network of leading healthcare multidisciplinary JoHD professionals.
- Accelerate research for the JoHD community.
- Learn what people with JoHD and their families need so we can improve support and education initiatives.
- Identify support, education and community resource connections for children and young people with JoHD and their families.

To achieve this HDYO has partnered with pharmaceutical companies, the HD Research community and networks, HD patient advocacy organisations and HD families. They have assisted in designing and developing a tailor-made registry that will capture experiences, health information and de-identified personal data from patients and their caregivers impacted by JoHD.

From January through to May 2020 we worked with the development team at Pharma International (subsidiary of Roche) to customise their content platform into the HDYO JoHD Registry Platform. The development phase gave us the first version of the platform to see what it would look like and how it would work.

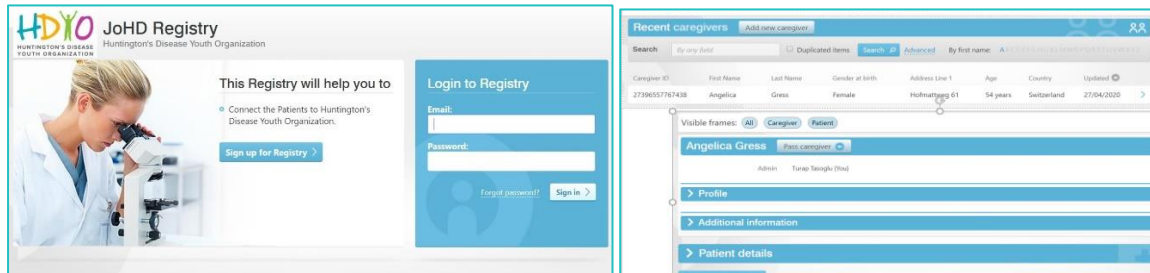
May through to October saw us engage with numerous partners across the whole HD community to make sure that the platform was viable and safe (similar to phase 1 of a clinical trial). This was a really vital piece of work as HDYO always wants to ensure we do our utmost to protect the privacy and security of people's data whilst balancing raising awareness! All the feedback led us to split the collection across two platforms instead of one. This means that when someone completes the personal information section of the registry their data will not sit on the same platform as their experiences or health information. This means if anyone ever tried to hack or steal the data they wouldn't be able to trace it to an individual (similar to how the Enroll-HD platform works)

Along with the development and testing of the platforms viability and safety, the Research Committee were working hard on developing study protocols to ensure we were ready when the time came to launch the full platform.

November and December was all about the protocols. We had submitted them to Enroll-HD Scientific Oversight Committee back in September and they gave us lots of positive feedback to help us make sure that we have everything written up properly.

We have made a huge leap forward on the JoHD Registry platform and we are nearly ready to launch registration in early 2021 with the next phase coming soon after that.

If you would like to know more about the JoHD Registry, please get in touch with the team on registry@hdyo.org



“This is amazing! How and when can the juvenile HD community participate” - Young adult, US

“I am interested in the JoHD registry, I will sign up” – Parent, USA

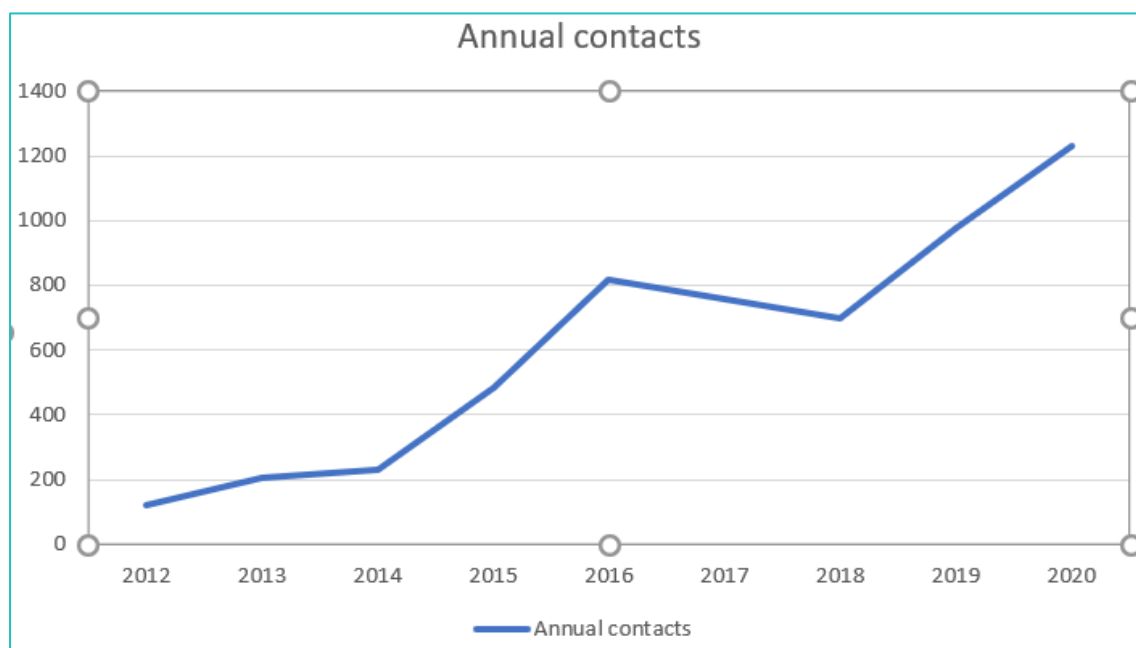
“Wow! What important work, Amazing!!” - Young adult, USA

“Yeessssss!! Finally, this is wonderful”- Parent, USA

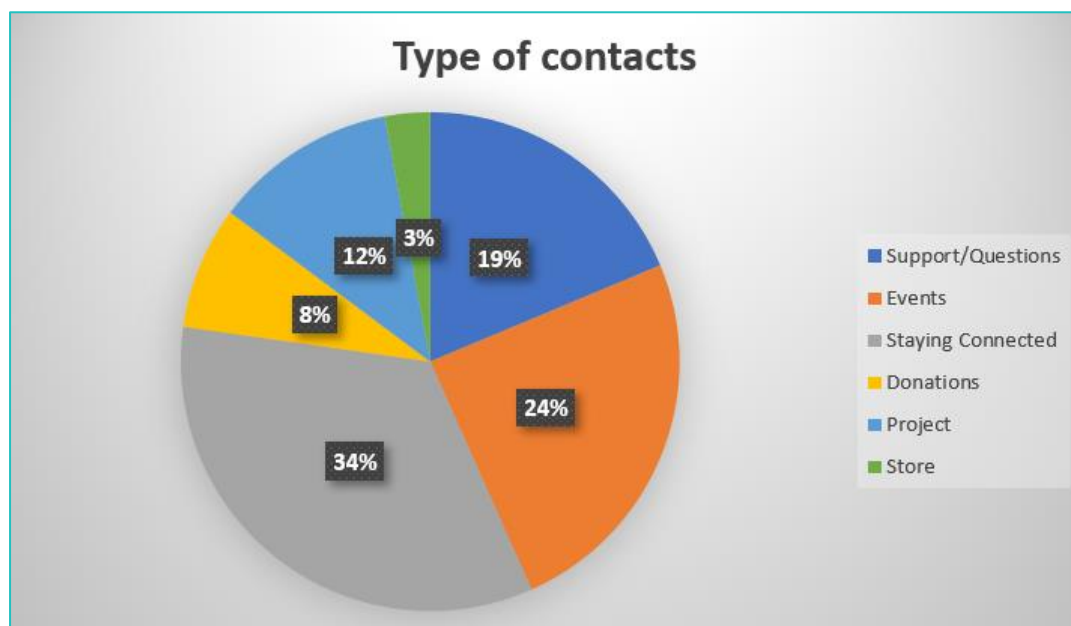
*“Lovely, ive shared this awesome information with 2 groups in Sweden! Great work!”
Young adult, Sweden*

Key Numbers For 2020

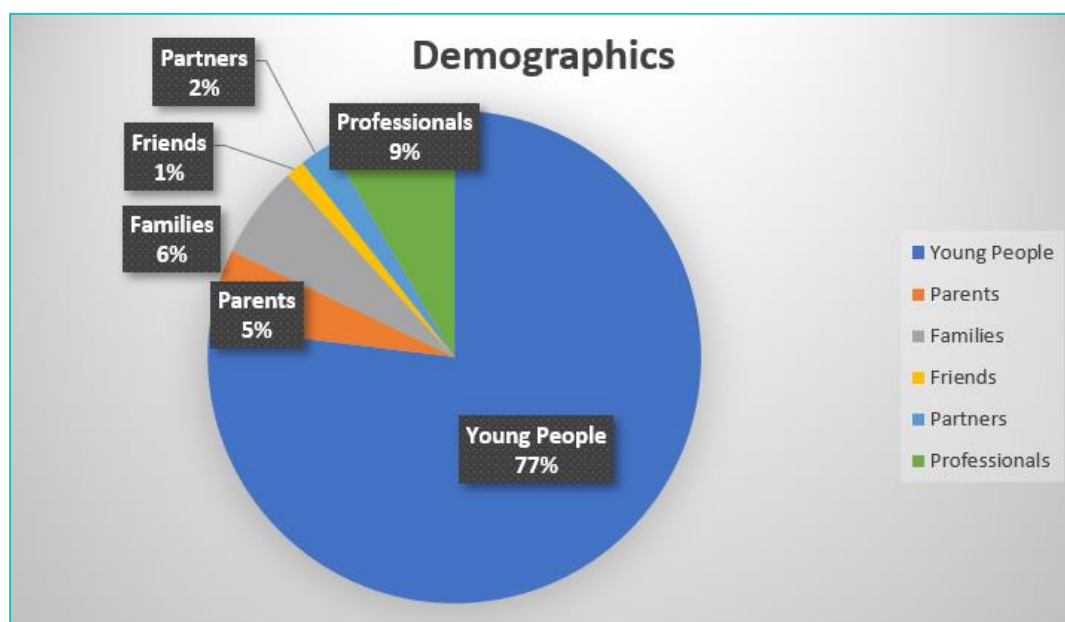
We broke our record for contacts from young people comfortably this year. A contact could be a question we’ve received, or someone attending one of our sessions, or us providing general support to a young person.



We made 1,230 contacts in 2020, our previous highest number of contacts was 976 in 2019. Contacts for 2020 focussed on congress registrations up until March (approximately 250 of them). We had a dip of contacts in March as lockdown begun but then we set up the Staying Connected program to provide regular opportunities over lockdown for young people and families to connect with us and each other on various topics. We kept the program going all year on a monthly basis. The program was our biggest contact point creating another 400 contacts. See more information below on how we've supported young people and the types of things people have been contacting us about.

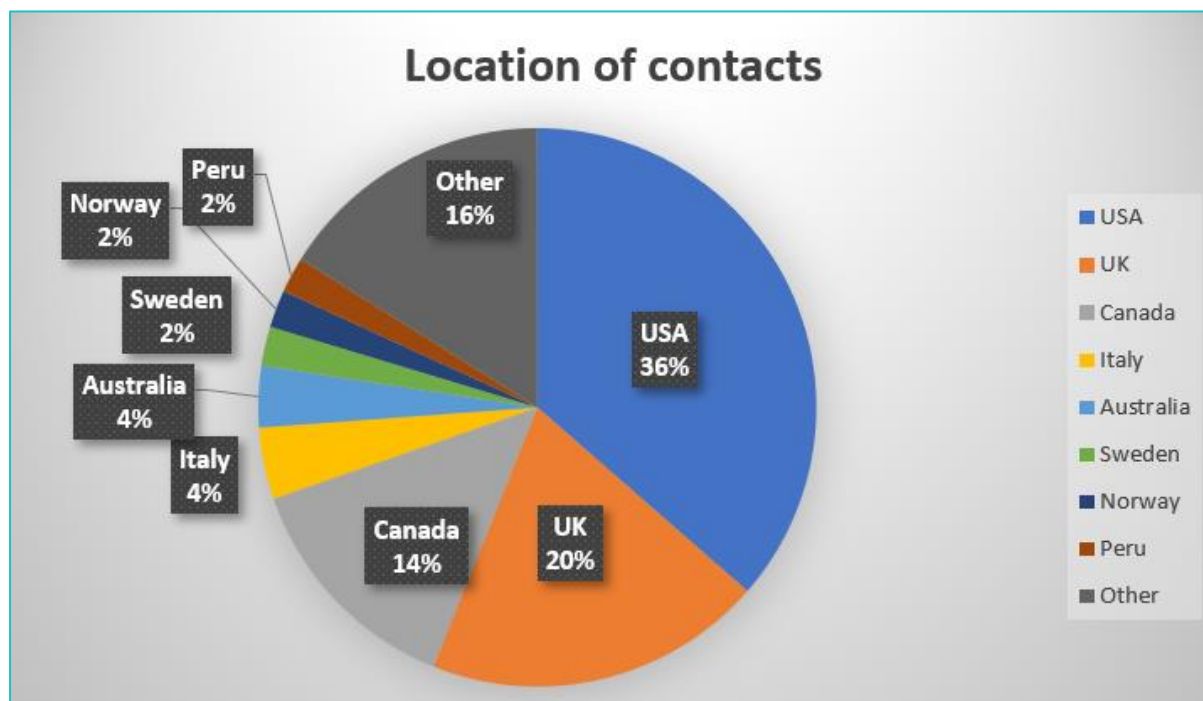


The graph below shows the types of people contacting us, we are proud to support professionals with educational material alongside supporting young people and their families and friends.



Where do the people contacting us live? it's the usual suspects at the top with the US, UK and Canada leading the way, but a strong representation from those below and notable mentions for Portugal, France, Belgium and Romania.

We have now had contacts from people from 98 countries!



Social Media:

YouTube: HDYO's video content is shared on YouTube, which is performing well with 5,000 subscriptions and 2.5 million video views!!! HDYO have the largest HD channel on YouTube of all the HD organisations.

Young Person Facebook Group: We are very proud to have 1,300 members of our young person closed support group on Facebook. Young people request to join and then have access to a supportive community where they can speak freely, ask questions and support each other together.

Parent Facebook Group: Our parent Facebook group currently has 150 members. This is for parents only where they can share their experiences while also supporting each other in a safe environment.

For other social media we have the following followers:

- Facebook: 12,500 followers
- Instagram: 1,300
- Twitter: 1,000

We have a program of content which is posted regularly on all the social media channels, ensuring that our community has regular news, updates and advice from us.

2020 Finance overview

Huntington's Disease Youth Organization

Financial Activities

January - December 2020

Income	
Donations and Grants	380,423.82
Event Attendance (Refund of congress registration)	-6,496.39
HDYO Congress	8,065.74
Merchandise	104.40
Refund	635.55
Services	38,550.80
Uncategorised Income	14,883.35
Total Income	\$436,167.27
Expenditures	
Advertising/Marketing	113.91
Bank Fees	196.91
Conferences/Conventions	23,271.59
Dues and Subscriptions	314.33
HR Service	35.12
Insurances	786.24
Interest paid	314.37
Office/General Administrative Expenses	1,084.36
IT Services/Software	2,373.24
Newsletter	746.71
Parking & Fuel	21.15
Phone	1,044.98
PO Box	502.50
Postage	472.05
Printing/Publishing	1,376.70
Storage Unit	3,094.11
Website	21,085.94
Other Professional Services	18,970.21
Paye & NI (Taxes)	36,231.67
Payroll Expenditures	1,426.94
Projects	744.76
T-Shirts	28.00
Staff Expenses	694.58
Professional Development	98.27
Travel and Accommodation	3,318.45
Airfare	1,160.15
Taxi/Parking	199.07
Travel meals	373.05
Wages / Salaries	111,614.74
Total Expenditures	\$231,694.10
Net Operating Income	\$204,473.17*

**This amount includes the income of \$150,000 received for the mentorship project, YLN expenses and Congress that was received in 2020 but is carried over and will be spent in 2021*

2021 Project overview and Request For Funding

Please see below for an overview of our projects planned for 2021, along with the assigned staff members and proposed milestones. To fulfil these projects in 2021, HDYO would like to be considered for a donation of \$90,000 from the Griffin Foundation.

Throughout 2020 we have worked hard as a team on HDYO's finances. We have been very diligent in 2020 to reduce our costs as much as possible. Additionally, we have been working towards reducing our financial dependence on the Griffin Foundation throughout the year. All this has given us an improved perspective and shown the need for a better grasp on our overall financial situation going forward. We have also implemented a strategy to make HDYO more sustainable moving forward. We plan to continue this detailed work ethic through 2021 and in the future.

We would propose the \$90,000 to be split across two payment milestones; one upon satisfactory delivery of Congress in mid-March, and the second after completion of the training of the first group of mentors by September (Mentorship project).

Project Name	Project Blurb	Staff/Board Member	Q1 2021	Q2 2021	Q3 2021	Q4 2021
Virtual Congress	Virtual Young Adult Congress	Matt, Chandler, volunteers & entire 9 person Board	Agenda designed, promotion, follow up and reminders for speakers Event	Follow up and surveys of participants and event feedback		Planning for in person meetings in 2022 (COVID depending and US and EU mini events)
Front line & Staying connected (continued project)	Online group support sessions on specific topics each month, engaging with Help 4 HD and working with HDSA	Matt / Mentorship contractor (to be hired)	Monthly sessions designed by young people in US and EU time zones. Speaking at Help 4 HD events and working together to publicise the JHD registry Working with HDSA and centres to refer any young people with more complex support needs to Jennifer and Mary Ann at HDSA. We are working closely with Chandler and Jen for a smooth hand over.			
Mentorship project (continued project)	Mentorship program for young people from HD families, peer to peer support, alongside HDSA	Chandler then handing over to mentorship contractor, oversight by Dr Bonnie Hennig Trestman	Training of Trainers (HDSA and HDYO staff), Complete open mentorship applications	Review applicants and plan training	Train participants (Group 1) and pair mentors and mentees	Train participants (Group 2) and pair mentors and mentees

Project Name	Project Blurb	Staff/Board Member	Q1 2021	Q2 2021	Q3 2021	Q4 2021
Young leaders' network (continued project)	Project to develop young leader networks in local regions around the US	Mentorship contractor/ Marketing and education committees on the board	Review current teams and fundraise during Superbowl Sunday and March madness	Open for new team captains and continue blogs and online fundraising	Train new team captains	Holiday fundraising campaign and support
Education: Matts Chats Series (continued project)	Monthly video interview series on a number of educational topics speaking to a wide range of experts	Matt and education committee on the board led by Dr Heather Ging and Donna Spencer	Monthly videos to be recorded, edited, and released on social media/website and YouTube			
Education project: HD Buzz video series (New project)	Working with the HD buzz team (Jeff Carroll and Dr Ed Wild) to produce short video updates of the popular blog for even easier accessible research news	Matt and education committee on the board led by Dr Heather Ging and Donna Spencer	Work with video editors Plan process with HD buzz	Continue to work on regular videos and post content in tandem with HD Buzz		
JoHD registry (continued project)	JoHD family database to build more understanding of the JoHD community	Study coordinator (currently hiring) and research committee on the board led by Dr Lauren Byrne and Dr Bonnie Hennig Trestman	Hire Study coordinator Release registration form	Release other fields of registry for completion	Monitor observational information collected	Review observational information collected from the community and further support