About HDYO

HDYO has more information about HD available for young people, parents and professionals on our site:

www.hdyo.org
The Huntington’s Disease Youth Organization is non-profit set up to provide support and education to young people (aged up to 35) impacted by Huntington’s disease (HD) around the world. View our definitions of ‘young people’ and ‘impacted by HD’ below. We are an official entity in both the USA (501c3) and United Kingdom (Charity Commission #1145781).

Our goals/what we do

Our goal is to provide support and education for young people impacted by HD globally. We do this through providing professional support online, creating needed educational content for all age groups (kids, teens, young adults, parents and professionals), making our site and content available in as many languages as we can, connecting young people with their peers, making events such as youth camps and conferences around the world, motivating and providing opportunities for young people to get involved and working with other HD organizations to improve what they offer young people also.

History of HDYO

Matt Ellison, a young person from and HD family, wanted to use his own experience of growing up with a parent who had HD to change the landscape for other children and young people. Matt had the opportunity to connect with other young people at the HD World Congress in 2009 where he met BJ Viau. These two young men along with other young people developed an idea into a reality that became HDYO.org, an organization dedicated to filling the gap in support and education for young people impacted by HD around the world.
Their passion and belief that children and young people need support, education and connections has enabled a global shift in HD community. After 2 years of fundraising, writing and researching, lobbying for partnership and engaging decision makers HDYO.org was officially launched in Feb 2012 as a non-profit with the web platform hdyo.org going live.

Since 2012 HDYO has grown and exceeds our expectations. We hired our first staff member, Matt Ellison (our founder) as Project Coordinator in 2013 followed in 2014 by Chandler Swope our USA Director of Youth Services. Our staff was and still is to this day supported by a working but voluntary board of directors and a dedicated global team of volunteers who help with everything from translation, feedback and fundraising to representing HDYO at events and being camp volunteers. As we have grown, so too has our teams. In 2017 we hired our first Executive Director, Cat Martin and expanded our Board of Directors.

Pushing and reducing boundaries has always been something that HDYO has tackled and will continue to challenge. Bringing opportunities such as our youth camps to Australia and New Zealand, Europe, North America and South America. Also, in 2018 we announced that we will hold the Inaugural World Young Adult Congress on HD in Glasgow, Scotland in May 2020!

Not only does HDYO provide professional services to children, young people and parents worldwide we also partner with clinicians, researchers and industry to ensure that the voices of young people and their families are included and heard! We are actively involved in social research programmes and directing interest to the impact and models of care for children and young people impacted by HD.

**Values**

We believe HDYO’s values are:
- Trust – we are an organization you can trust
- Positivity – we take a positive approach to HD
- Community – we try to help our community to grow
- Passion – we are passionate about helping young people impacted by HD around the world

**Full Time Staff Team**

We currently have 3 full-time staff Cat Martin (Executive Director), Matt Ellison (Project Coordinator) and Chandler Swope (Director of Youth Services in the US). Learn more about our staff team here.

**Board of Directors**

Our board is made up young people from HD families, professionals in the HD community and others who are passionate about the cause. Are you interested in taking on a board role with HDYO? Please email us about your interests! Learn more about our board here.

**How we are funded**

We are funded by a mix of grants, community donations and HD Association support for our work. We are always keen to hear from anyone who thinks they could help us financially as we are a small organization who achieve a lot with not many resources. Would you like to support our work? Please reach out to us about making a donation or hosting your own HDYO fundraising event. We would love the opportunity to work with you!

**HDYO’s Definitions**

**What is a young person?**

We consider a young person to be up to the age of 35 and our services are designed for those ages, although our educational content is useful for all ages and we encourage anyone to contact us if you need support, we will aim to get you to the right place.

**What do we mean by ‘impacted by HD’?**

We use the word ‘impacted’ because it includes many more people than just the person who has HD. That person is affected by HD, but many people can be impacted by HD who don’t have HD at this moment. So impacted by HD, for us, includes:

- At risk for HD
- In a family with HD (whether yourself at risk or not)
- Know someone with HD
- In a relationship with someone impacted themselves by HD in some manner
• A young person who has tested positive or negative for HD
• Diagnosed with HD or Juvenile HD
• Learning about HD for educational purposes – e.g. a school project
• Feeling concerned about HD for any reason

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https://en.hdyo.org/eve/about/28

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