



**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**

Five Year Strategy



SUPPORT, EDUCATE, EMPOWER



Commitment to Our Mission

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

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

Who We Help:

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

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

What We Currently Do

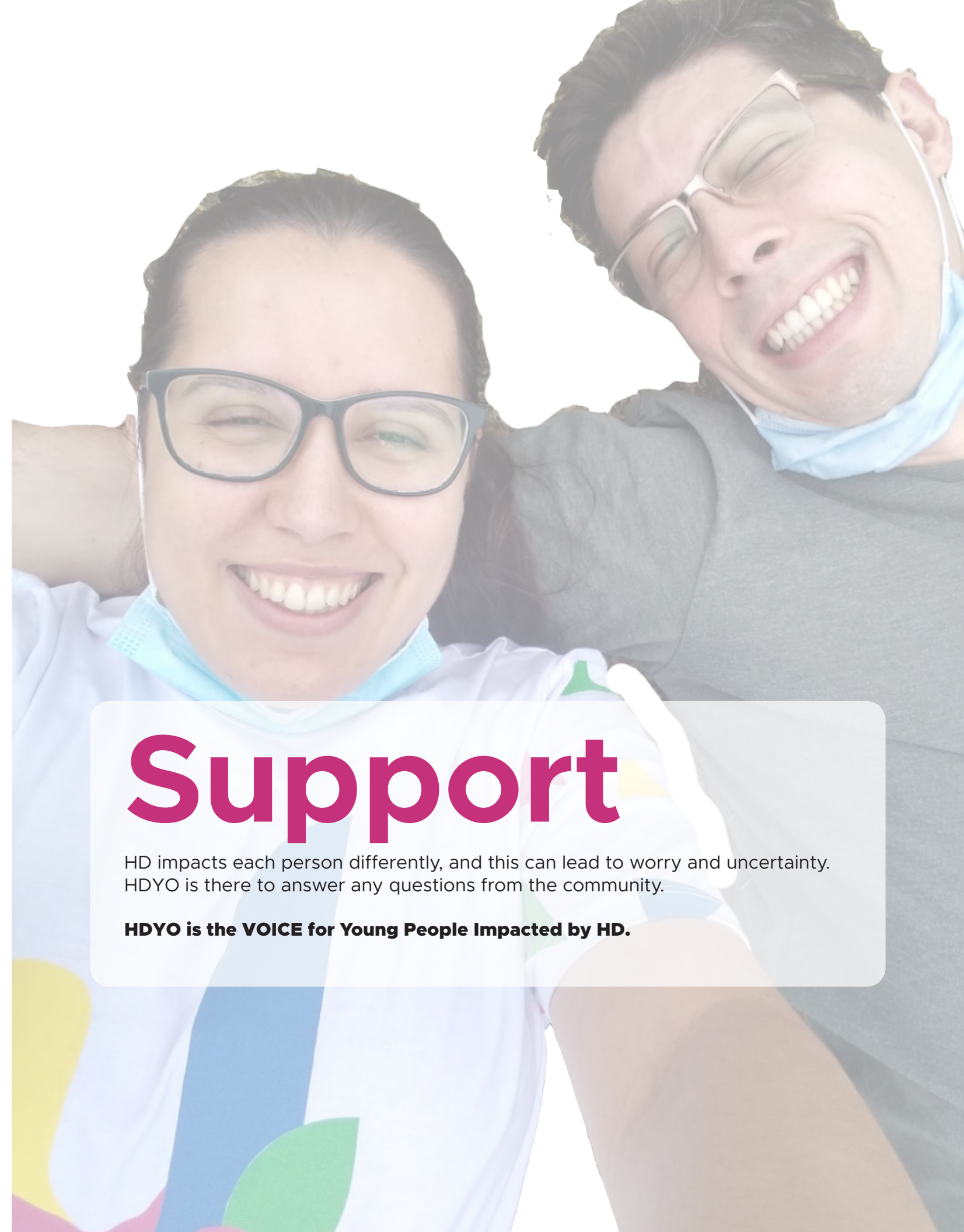
HDYO.org – **The center of our support & education.**

- **14 languages** & huge range of content for different ages.
- Nov 2021, we launched our new redesigned website with the **new branding & enhanced navigation.**
- Direct support is provided by our staff.

Educational Programs

- **JOIN-HD: The Juvenile-Onset Initiative for Huntington's Disease** - A Global Registry to connect the community of those affected by JOHD, increasing the understanding of the disease & encouraging future research.
- **HDYO International Congress** - A program of insightful talks, sharing, research updates, peer support & fun!
- **Youth Mentorship Program in Partnership with HDSA** - This program provides a young person (mentee) with one-on-one time with another person (mentor) who will receive training, & ongoing support
- **International Ambassadors** - Young people who bring real-life experiences to better advocate for the entire community.
- **Research Video Series** - In partnership with HD Buzz, we develop frequent videos to showcase the latest news in HD research.
- **Breaking Down Barriers Series** - We tackle the stigmas surrounding HD
- **HDYou Community Stories** - Featured interviews with members of the HD community.

The following details new programs and enhancements for the next five years at HDYO as we continue to be the voice for young people!



Support

HD impacts each person differently, and this can lead to worry and uncertainty. HDYO is there to answer any questions from the community.

HDYO is the VOICE for Young People Impacted by HD.

SUPPORT

Youth Social Workers

HDYO Youth Social Worker:

This part-time social worker would help connect the HDYO team to social workers & provide support in several areas of HDYO.

- Triage requests & questions from the community
- Make referrals for local HD associations & support
- Provide social worker perspective to HDYO.org content & blogs
- Help design useful tools to be given to the community of social workers & clinics.

International Youth Social Worker Network

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

- Convening social workers for peer support
- Continuing Education
- Database of Social Workers
- Access to a variety of materials & resources
- Encouraging global collaborations

Youth Mentorship/Mentee Program

In the US, HDYO partnered with HDSA to begin this program. Immediate goals are:

- Recruit for both mentors & mentees at in-person events
- Continue online recruitment
- Review application process to increase ease of completion
- Host training in-person
- Provide data to HDYO Research Committee

Internationally, there could be also be implementation of this program. We hope to identify key partners who could help with the implementation locally.

In Partnership With



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

Bhairavi
Mentor - Michigan





In-Person Events

International Young Adult Congress

The first two years of the Virtual Congress has been a huge success. That has inspired us to restart planning efforts for our in-person Congress in Glasgow.

- Host Congress every other year starting in 2023
- Engage with local associations
- Provide scholarships to attend
- New Location each Congress
- Host Hybrid Options
- Create planning committees
- If funding allows, bring on an additional staff member

Camps

The marquee program of HDYO has been youth camps. There is a real need for programs to come back in person because of the drop of support for young people. Both financial & staff resources need to be considered.

- Host camps every other year in a different country (target start date in 2024)
- Engage with local associations
- Create planning committees to help with organization
- If funding allows, bringing on a staff member to help with planning.

Educate

HDYO strives to educate and provide resources for the community to support them through every part of their journey with Huntington's Disease.

HDYO is the HUB for Resources

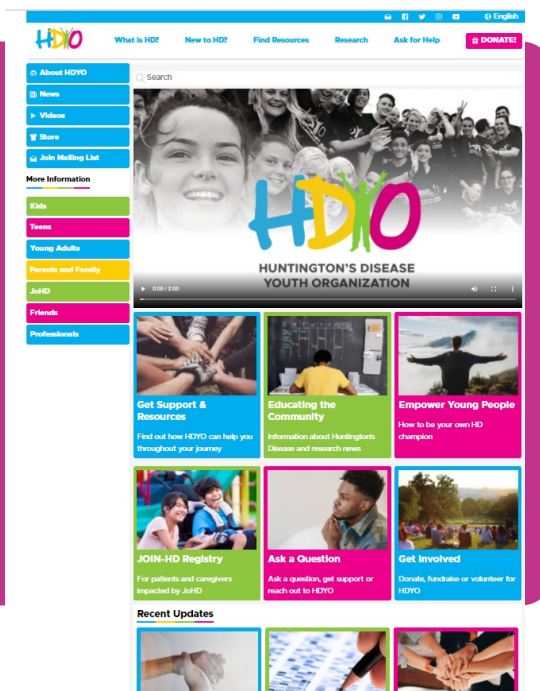


EDUCATE

HDYO.ORG

Now that the enhanced navigation and re-branding of HDYO.org is complete, committee members are participating in an extensive content & resource review. Items include:

- Article Updates
- Unveiling Opportunities for Additional Content
- Educational Blogs
- Updated Flyers with new branding
- Convene with social workers & medical teams on usefulness & need for additional tools when working with the community.



Surveys

The need & manner in which the HD community searches for & receives resources has been greatly impacted by the pandemic. In addition, HDYO has developed a strategy for our approach. We will be implementing a series of surveys to help in certain key areas & we are seeking IRB approval.

Surveys will consist of topics such as:

- How does the community use/search for resources?
- What information does the community know about participating in research & other areas of stigma?
- What is the life cycle of young people seeking support & getting involved?

Surveys will be disseminated through partnerships with other organizations, social media including support groups & through other HD partners. The results would be shared at a variety of conferences

Breaking Down Barriers

This program was designed in 2021 to tackle stigmas around clinical research. This program has caused the most excitement in the community. We are committed to expanding this program to include several new perspectives:

- Develop future videos to include a young carer's perspective, access to research & speaking to children about HD.
- Expand partnership across associations & organizations.
- Host casual conversations with partners on social media.

We are actively seeking additional partners to help support & use this project to share to their databases.



HDYou: Community Stories

Launched in 2021, Matt's Chats focused on one-on-one conversations with members of the community. We have a great opportunity to develop this program & make it a way to engage and share unique perspectives. We have rebranded this program as HDYou: Community Stories.

We will host, as a minimum monthly segments which will last between 30-45 minutes. These will feature; perspectives which empower, personal stories, ways to get involved & scientific updates. Hosts will include HDYO staff, Ambassadors & other community members. These will be published with the additional capabilities of closed captioning in multiple languages on both YouTube & Facebook Premiere.

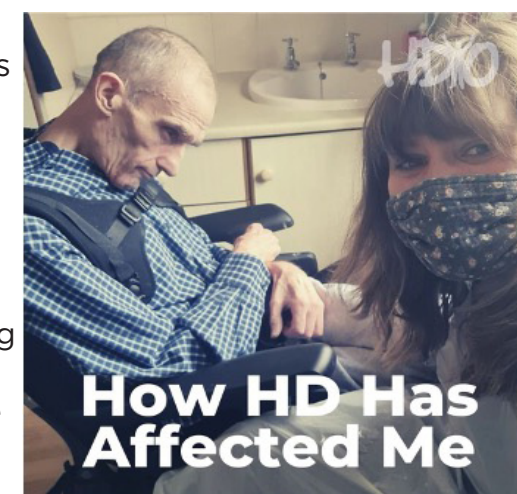




HDYO Ambassadors

Starting in 2021, the HDYO Ambassador Program has been well-received. There is an opportunity to expand their roles at HDYO. Some of these areas were originally planned but have been delayed due to the pandemic.

- Host mentorship-type training to select Ambassadors who would like to become more engaged with offering support
- Involvement in HDYO programs such as HDYou, Breaking Down Barriers, Camps & Congress.
- Provide peer-to-peer support when someone would like to hear their perspective.
- Encourage participation in HDYO programs
- Disseminate information to local associations.
- Assist with fundraising efforts
- Serve as the “boots on ground” internationally for HDYO.



Empower

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

Clare raised funds by running a half marathon.

Get Involved



HDYO consists of amazingly dedicated community members. It is our goal to get more individuals involved. Ways of getting involved include:

- Increasing Ambassador Numbers
- Encouraging New Volunteers for Committees
- Re-engaging with Camp Participants
- Encouraging Fundraising
- Use survey results on the life cycle of engagement to create a campaign of outreach



The JOIN-HD Registry has officially launched to begin enrollment. This is an invaluable program from HDYO, but it doesn't necessarily represent the organization's advocacy programs.

Our goals for this next phase of JOIN-HD will help make this program successful and self-funded.

- Create a new website just for JOIN-HD that is linked from HDYO.org
- Approach pharmaceutical companies for grants associated with their research initiatives
- Seek out grant opportunities from research foundations.

Enhance Marketing

- Personal communication from SOC members & the HDYO team
- Presentations & posters at research conferences
- Separate social media channels
- Instructional videos
- One-on-one meetings with partners to encourage help with recruitment

Investing In People

Staff Additions: (Funding Dependent)

- Part-time social worker
- Program Coordinator to Manage Camps & Congress
- Admin Support

Board Additions:

- Vice Chair
- North American Chair
- Clinician
- Geneticist
- International Marketing Specialists
- Fundraising Specialist

Committee Additions:

- Education Committee – Recruit additional mental health professionals
- Advocacy Committee – Recruit members in the US
- Research Committee – Recruit clinician to co-chair & add members from Asian/Pacific countries.
- Marketing Committee – Recruit specialists in International Marketing & Social Media

HDYO Staff



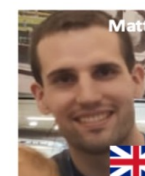
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