



MID 5-YEAR STRATEGY REPORT



CONTENTS

03

WITH GRATITUDE

04

HDYO AMBASSADORS

05

SUPPORT SERVICES

06

IN-PERSON PROGRAMMING

07

VIRTUAL PROGRAMMING

08

RESEARCH & ADVOCACY

09

THANK YOU



WITH GRATITUDE

Dear HDYO Community,

As we reach the halfway point in our [five-year strategy](#), we are excited to share the progress we've made and the steps ahead in our mission to support young people impacted by Huntington's Disease.

First, we want to express our heartfelt gratitude to each of you - our supporters, partners, and community members. Your commitment has been the cornerstone of everything we've accomplished so far.

Reflecting on Our Progress

Over the past two and a half years, we've made significant strides toward our goals. Some highlights include:

- **Expanding Access to In-Person Programs:** We've engaged over 400 young people and families through our International Young Adult Congress, North American Camps and Youth & Young Adult Mentorship program, ensuring young people feel supported and less alone in their journey.
- **Raising Awareness:** Through initiatives such as our survey series, we've engaged over 600 young people globally, to understand the unique challenges our community face when impacted by Huntington's Disease, the support young people need and their experience of research.
- **Strengthening the Community:** Our Ambassador program, HDYou stories, other online resources and outreach are providing a community for young people to empower and inspire each other.

These milestones reflect the dedication of our team and the unwavering support from donors, partners and advocates like you.

Looking Ahead

While we celebrate these achievements, we know there is much more to do. In the coming years, we are focused on:

- **Expanding Outreach:** Reaching underserved areas to ensure no young person faces Huntington's Disease without support.
- **Enhancing Resources:** Developing new tools and programs, including the STRIVE network, a digital platform tailored to health professionals working with young people impacted by HD.
- **Research That Advocates for Change:** Partnering with advocacy groups, research organizations and industry partners to lead projects such as JOIN-HD, which will inform resources and recognition of Juvenile HD.

Your continued involvement will be critical as we advance toward our vision of a world where young people impacted by Huntington's Disease have the resources, support, and hope they need to thrive.

How You Can Help

As we move forward, we invite you to stay involved:

- **Spread the Word:** Share our mission with friends, family, and colleagues.
- **Volunteer or Participate:** Join us at upcoming events like our International Congress in Prague or lend your skills to our initiatives.
- **Donate:** Every contribution, no matter the size, helps us make a difference.

Thank you for being an integral part of this journey. Together, we have accomplished so much, and together, we can ensure a brighter future for young people impacted by HD. If you have questions, ideas, or would like to learn more about our next steps, please don't hesitate to reach out at info@hdyo.org.



Dr. Ariana Mullin
HDYO Chair

HDYO AMBASSADORS



We've grown our Ambassador program - they are the heart and soul of this organization and the foundation of the what, why, and how we are able to do the work we do.

Our 100+ Ambassadors, representing nearly 30 countries, have connected this community together in new and creative ways.

From an HDYO perspective, Ambassadors host local fundraisers, provide experiences in support settings and participate in online programs like HDYou Community Stories and Breaking Down Barriers. They share tips for monthly topics about being impacted by HD, provide insights to HDYO programs like Congress and Camp and give feedback to partners who need to understand how young people think and feel about different topics. For the past three years, dozens of Ambassadors have bravely taken over HDYO social media channels to talk about relationships, their journeys and how they cope.

From a community perspective, Ambassadors provide a safe home for each other and support from people who "just get it". Ambassadors regularly lean on one another through difficult transitions, moments of need and life celebrations. New relationships and even extended families have been created through our Ambassador group. They serve as friendly faces to the community on social media, and their stories inspire others to reach out to HDYO or support services for often the first time.

I don't have a lot of family support, much less support from local friends. It can be quite lonely and isolating. This group has become my adopted family. I have learned about what's going on in the HD space on a global level, and I am now a global advocate, because you are my family. Having close-knit community like this, when dealing with such a devastating disease is so important. It provides hope and life and happiness in an otherwise dismal situation.

AMBASSADOR - U.S.

SUPPORT SERVICES

SOCIAL WORKER

Jacky Tse joined our team in early 2024. He is a registered social worker and obtained a MPhil in Education and Gender Studies from University of Cambridge with a background working with mental health for marginalized youth communities. Jacky is the main point of contact for anyone asking for support or advice from HDYO. Each introductory meeting allows the community member to share their story, so we can make recommendations and connect them with resources or services locally and globally. We work closely with our partners, to ensure that these young people have as much support as possible based on their individual needs. Jacky has also been authoring articles for our STRIVE network below and on hdyo.org to assist and educate professionals, who work with young people impacted by HD.



HDYO STRIVE NETWORK

Access to information and professional networks supporting young people varies greatly across regions. HDYO is proud to be finalizing a platform to bridge this gap through the HDYO STRIVE Network (Supporting and Training International Voices to Excel). Equipped with tools to meet other professionals, chat features to connect directly on the site, document sharing functionality and continuing education, this network will be available for enrollment in 2025. As a part of the STRIVE initiative, we have created new resources and guides for professionals, to better understand and work with young people in the HD community.



Professionals



IN-PERSON PROGRAMMING

To support our in-person programming, we've been able to successfully create scholarship opportunities for the community. We have also welcomed a new Program Coordinator, Marisa Pecoraro, to help manage all the behind-the-scenes logistics that makes these opportunities possible!

NORTH AMERICAN CAMP

For the first time since 2019, and with resounding excitement, we welcomed nearly 40 young people from Canada and the United States to Maryland in August, for the 2024 North American Camp. Our North American Camp continues to be a transformative experience for young people impacted by HD, with 70% reporting an improvement in their coping skills after attending. Campers continue to share their feedback on this program, and we are actively evaluating how we can expand Camp to new locations to reach different communities. In doing so, we will consider both partnership opportunities with local organizations, as well as identify communities where local resources are scarce, and the need is high.

INTERNATIONAL YOUNG ADULT CONGRESS

After two online conferences, HDYO was able to offer the first in-person International Young Adult Congress in Glasgow, Scotland. Held in March 2023, this event featured over 40 speakers, representing six continents, with 341 attendees from 26 countries. Building on the success of this first event, we are excited to host a second in-person congress scheduled for March 2025 in Prague! With support from our key sponsors, we will provide an estimated 100 scholarships for young people, with attendees across North and South America, Europe, the UK, Africa, Asia, and Oceania.

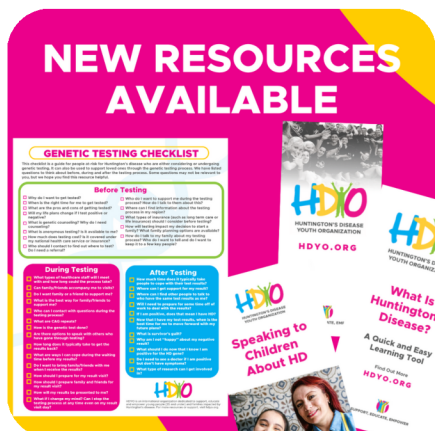
YOUTH & YOUNG ADULT MENTORSHIP PROGRAM

We are grateful for our collaboration with HDSA's National Youth Alliance! Over the past 3 years, we have recruited, trained and held both virtual as well as in-person training sessions. All mentors (100%) strongly agreed that the training program made them feel ready to be a mentor. The majority of mentees (85%) reported being glad to be a part of the program based on their current pairings. It has been a privilege and a joy to see numerous mentees grow into amazing mentors themselves. We will continue to obtain feedback from mentors and mentees, to understand their experiences and enhance this exciting program.



VIRTUAL PROGRAMMING

WEBSITE & ONLINE RESOURCES



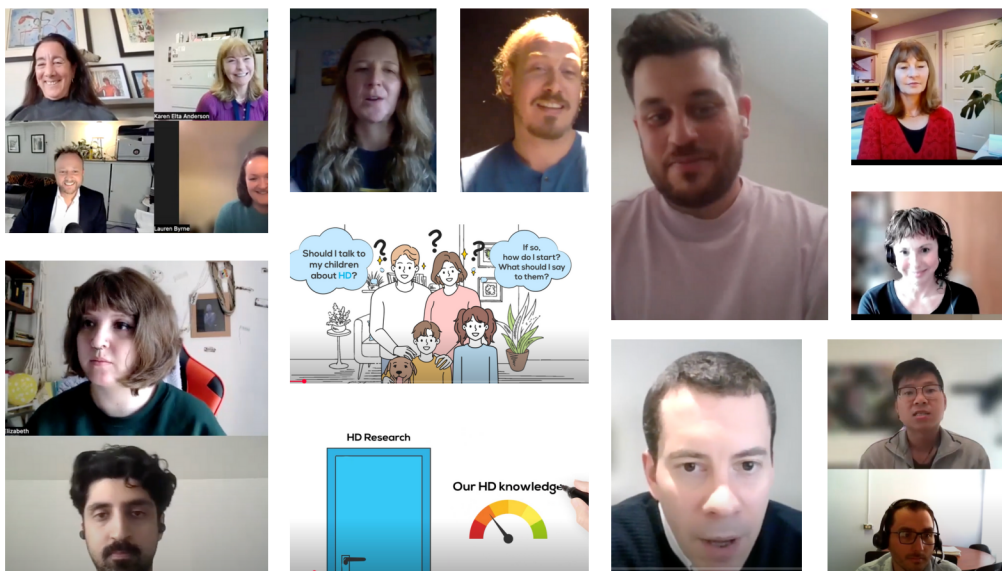
Our website, HDYO.org, continues to be an evolving information hub, meeting the growing needs of our community and our programs. Our team reviews website content on a regular basis, with a focus on ensuring that our young adult resources are up-to-date and accessible. Importantly, our social media channels are also expanding and serve as another easy-to-access repository for our video series. In conjunction with our education and research committees, we updated our key brochures to educate professionals and community members alike, about HD, how to talk to children about HD, and the services HDYO provides.

BREAKING DOWN BARRIERS

Breaking Down Barriers, launched in 2021, has become a true staple of HDYO with 28 videos produced. These videos reached over 185,000 people, through social media views and promotion. Initially designed to address stigmas about HD, HDYO continues to expand the program to include a variety of topics that are of interest to the community. In 2024, we produced and aired 13 videos, with translations. Two white board animated videos are in final production, describing the young person's HD journey and family planning options.

HDYOU COMMUNITY STORIES

The HDYou Community Stories are a natural extension of our video series initiatives. We've been overwhelmed by the positive feedback in response to hearing the stories of community members undergoing genetic testing, symptom searching and difficult conversations while dating. We have hosted 27 conversations, with a reach of more than 200,000 people through social media and promotion.





RESEARCH & ADVOCACY

SURVEY SERIES

Implementation of our survey series has provided incredible insight. We are grateful to the 600 respondents who have provided feedback, to help us better understand the needs of our community. Feedback from these surveys directly informs the resources and support we provide to the community, ensuring our resources and support strategies are evidence-based and meaningful. The results of these surveys have been presented at several international and community conferences. There is interest from our scientific partners about how they may improve their research and communication strategies to support young people.

JOIN-HD REGISTRY

JOIN-HD has undergone tremendous changes, and in 2025, it will be launched on a new, tailored-made platform to better support registry aims and participant experience. To date, we have 100 pre-registrations and 52 fully enrolled participants. Existing participant data will be seamlessly migrated onto the new platform and newly enrolled participants will be directed to our new platform, available in multiple languages to support access. To facilitate these changes, Casey Edwards was hired as the JOIN-HD Registry coordinator. She jumped into the role to immediately find a new platform with better access for the global Juvenile HD community.

HD COMMUNITY ADVISORY BOARD

A partnership between the European Huntington Association (EHA), International Huntington Association (IHA) and HDYO, HD-CAB has recruited 40 advocates from 27 countries, to provide their perspectives to research partners. Over the past 3 years, we have hosted 14 advisory boards, 12 educational sessions and the first international round table discussion. After participating in advisory boards, 84% of advocates reported their knowledge of HD research had improved (11% of the advocates identified as too new to HD-CAB to assess their improvement).



THANK YOU!

HDYO remains steadfast in our commitment to every young person impacted by Huntington's Disease. The breadth and depth of the resources we provide are a testament to the unwavering support of our community. It's truly inspiring to witness the impact of these efforts. From our educational programs, to our engaging video series and transformative in-person events, the diversity of our resources ensures we can make meaningful connections with young people from all walks of life, meeting them wherever they are on their unique journeys. We continue to be in awe of our Ambassadors, the Gimbel Family Scholarship Fund, HD Heroes, Livable Lives, and the countless people whose financial and volunteer support fuels HDYO. Together, we are creating a brighter, more hopeful future for every young person impacted by HD.

PROGRAM SPONSORS

Over the past 2.5 years, we are thankful for the support from key partners, ensuring our programs can continue to make an impact for young people.

