HDBUZZ

# The Huntington's Disease Youth Organization's World Congress: Supporting Young People Affected by HD

**Young people impacted by Huntington's disease don't have to face it alone. @HDYO provides support, education, and community to empower those up to age 35. Learn more about their mission and the recent HDYO International Young Adult Congress!**

**By Dr Sarah Hernandez | March 17, 2025 | Edited by Dr Rachel Harding**

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The Huntington's Disease Youth Organization (HDYO) is an international non-profit dedicated to supporting, educating, and empowering young people up to the age of 35 who are impacted by Huntington's Disease (HD). Founded in 2012, HDYO provides a safe space for young individuals and their families to access resources, connect with peers, and find professional support. During HDYO's International Young Adult Congress held in Prague, Czech Republic on March 14-16, HDBuzz was honored to be in attendance, sharing accessible, research-driven insights to empower young people affected by Huntington's disease.

## A Mission Focused on Young People

HDYO's work revolves around three key areas: **support, education, and empowerment**. **Support** is at the heart of the organization's mission, ensuring that no young person faces HD alone. The organization provides peer-led support groups where young people can share their experiences in a safe environment. Professional support services also help connect individuals with resources in their communities, ensuring they receive the guidance they need.

*HDYO hosts a biennial International Young Adult Congress—an event designed by and for young people impacted by Huntington's disease. The 2025 Congress took place March 14-16, 2025 in Prague, Czech Republic.*

**Education** is another crucial aspect of HDYO's mission. The organization simplifies the complexities of HD through accessible, age-appropriate resources. These materials help young people of all ages and their families understand the disease, learn about its impact, and stay informed about the latest research. By making scientific information more digestible, HDYO bridges the gap between complex research and everyday understanding.

Beyond support and education, HDYO **empowers young people** to become advocates for themselves and their families. Through personal storytelling, mentorship, and leadership opportunities, the organization helps young individuals develop confidence and a sense of agency. Erasing stigma and fostering resilience within the HD community are fundamental goals of this empowerment work.

# What Makes HDYO Unique?

HDYO stands out as the only organization dedicated exclusively to supporting young people affected by HD. Its youth-centric approach ensures that all programs and resources are tailored to the unique challenges faced by young individuals. This includes navigating the decision of whether or not to have a genetic test for HD, care-giving responsibilities for loved ones, especially parents, struggles with social and romantic relationships, as well as challenges to typical education and career paths.

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The organization provides a vast array of online and in-person resources, making vital information accessible to young people around the world. These include educational videos, interactive tools for understanding HD, guides for parents and professionals, and virtual and in-person support events. Importantly, HDYO's website and resources are available in multiple languages, ensuring global accessibility.

A key part of HDYO's impact comes from its international presence. Through initiatives like the International Representatives program, the organization extends its reach by engaging young volunteers who spread awareness and provide localized support. This model ensures that HDYO's mission resonates with and benefits communities worldwide.

# The HDYO International Young Adult Congress

One of HDYO's flagship initiatives is the International Young Adult Congress, a gathering designed by and for young people impacted by HD. The 2025 Congress took place last weekend, March 14-16, in Prague, Czech Republic, bringing together young people from across the world for education, connection, and advocacy.

*HDBuzz's Dr. Rachel Harding delivered two talks at the event - one on Huntington's disease research terminology, and a research breakdown of the exciting updates and advances we've had over the past year.*

The event's agenda was structured to address the most pressing concerns facing young individuals in the HD community. **Day 1 focused on mental health and community-building** , creating a safe space for attendees to share their experiences. Discussions around self-care, grief, and loss helped participants develop coping strategies while interactive sessions encouraged networking.

**Day 2 highlighted scientific understanding and personal narratives.** Attendees learned about the latest HD research, clinical trials, and treatment developments through accessible presentations. Alongside this, community members shared personal stories about relationship dynamics, communication challenges, and cultural perspectives on HD.

**Day 3 provided practical guidance and future planning** on topics such as family planning, maintaining a healthy lifestyle, and navigating life after genetic testing. Sessions also explored complex emotional topics like survivor's guilt and strategies for living at risk. These discussions offered attendees the tools and knowledge to make informed decisions about their futures.

# Why Awareness of HDYO Matters

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> **young people affected by Huntington’s Disease. Through its unique focus on youth, accessible educational materials, and global outreach, the organization plays a critical role in the HD community. ”**

It is essential that young people affected by HD know about HDYO—they are a unique resource for those navigating the challenges of growing up in a family impacted by HD, offering guidance, reassurance, and community support. For many, discovering HDYO provides a sense of belonging and understanding that may be difficult to find elsewhere.

Equally important is ensuring that adults—whether family members, educators, or healthcare professionals—are aware of HDYO’s work. By understanding the resources available, adults can better support young individuals, guiding them to the information and communities that will help them navigate their HD journey.

# A Community Built for the Future

HDYO is more than just a resource; it is a movement dedicated to uplifting young people affected by Huntington’s Disease. Through its unique focus on youth, accessible educational materials, and global outreach, the organization plays a critical role in the HD community. Events like the HDYO Congress reinforce the importance of connection and knowledge-sharing, ensuring that no young person has to face HD alone.

Increasing awareness of HDYO’s mission is vital for the next generation. Whether through online resources, peer support, or global events, HDYO continues to provide young people with the tools they need to face the future with confidence. If you know a young person impacted by HD, consider sharing HDYO’s resources with them—your support could make all the difference in helping them feel informed, connected, and empowered.

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*The authors have no conflicts of interest to declare.For more information about our disclosure policy see our FAQ...*