





WELCOME!

We are so thrilled to have each of you in Prague, for our International Young Adult Congress!! After our first in-person Congress in 2023, we were renewed by the importance of an event like this, for the global community of young people impacted by Huntington's Disease.

This event is designed for YOU! We have a variety of sessions based on the interests of young people impacted by HD. Those range from mental health sessions to understanding research to interactive panels with shared experiences and stories. You can choose what resources will be the most impactful for your needs.

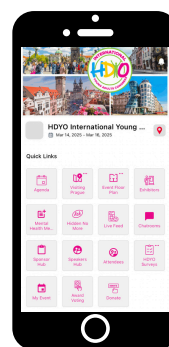
We are so thankful for the dozens of associations and sponsors, who have supported more than 150 scholarships, for young people to attend this weekend!

We hope you walk away with new friends and feel empowered to be your own advocate.

The HDYO team is here to help in any way. We hope you enjoy!



Jenna Heilman
Executive Director
HDYO



**Have you
downloaded the
Congress App, yet?**

**Search your email
for vFairs or visit
the HDYO Desk for
help.**





Friday

14
MAR

10:00

Registration and Exhibit Hall Open

11:00

First Time Event Attendee/New to HD Meeting

- *Speakers - Matt Ellison, Ashley Clarke,*
- *Room - Ambassadors' Room - Tycho/Kepler*

11:00-12:30

Lunch Foyer & Meridian

12:15

Opening Ceremony

- *Room - Meridian*

13:30

Preparing for Congress

What are some tools in your toolbox as you attend Congress, including self-care and resources available during the weekend.

- *Speaker - Dr. Bonnie Hennig-Trestman*
- *Room - Meridian*

14:30

Break/Exhibitor Hall

15:00

Get To Know Your Table

Make new friends with fun games.

- *Room - Meridian*

15:30

Understanding Grief & Loss

Grief and loss can happen at various times throughout your experience with HD. Learn about how to manage through those times.

- *Speaker - Dr. Robert Trestman*
- *Room - Meridian*

16:00

Break/Ehibitor Hall

16:15

Speed Dating

Get to know other attendees, based on similar interests.

- *Room - Meridian*

17:30

Art4HD

Exciting reveal of new mural in Prague about HD.

- *Room - Meridian*

Explore Prague

Make a plan with friends, to enjoy a dinner at one of the many Prague restaurants, or relax before the next day.



uniQure is Proud to
Sponsor the 2025
HDYO Congress

uniQure

ASHLEY / Huntington's Disease
Community Advocate



Targeting the Cause, Changing the Future of HD

Advancing Science, Supporting Community,
Fighting HD Together.

Learn about our RNA-targeting
small molecules
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SKY-0515

 **SKYHAWK**
THERAPEUTICS



Saturday

Breakfast will be served in the restaurant at the main level of the hotel.

15
MAR

9:00

Let's Get Ready for the Day

Review the day

- Room - Meridian

This Is Research Terminology!

Join the interactive discussion about different terms you will hear in HD research. Don't miss out on fun prizes!

- Speaker - Dr. Rachel Harding
- Room - Meridian

10:25-11:00

Concurrent Sessions (Choose one of the following)

Talking About HD - Learn the basics of Huntington's Disease and how to speak about it to friends and family.

- Speaker - Cat Martin
- Room - Taurus/Aquarius

Spilling the T on Gene Therapy: An interactive look at this therapy.

- Speaker - Jacose Bell (Spark Therapeutics)
- Room - Zenit

Taking a Whack at Mutant Huntingtin

- Speaker - Dr. Asela Bandara (Wave Life Sciences)
- Room - Nadir

Dual Perspectives Q&A - This hour-long session will hear experiences from two family members, with a variety of relationships with Huntington's Disease.

- Facilitator - Jenna Heilman
- Panelists - Meg, Claudia, Taylor, Holly
- Room - Tycho/Kepler

11:10-11:40

Concurrent Sessions (Choose one of the following)

Measuring What Matters: Present & Future Clinical Trial Endpoints

- Speakers - Dr. Jonas Dorn & Dr. Peter McColgan (Roche)
- Room - Zenit

Impact of Advocacy on Research - Explore how your voices can make a difference in research

- Speaker - Astri Arnesen
- Room - Taurus/Aquarius

Dual Perspectives Q&A - This hour-long session will hear experiences from two family members, with a variety of relationships with Huntington's Disease.

- Facilitator - Jenna Heilman
- Panelists - Drake, Francesco, Sadie, Wes
- Room - Tycho/Kepler

11:40-12:40

Exhibitor Hall & Lunch (Included with Registration)

Restaurant Veduta on Reception Level; Exhibitors in the Foyer.



Saturday

15
MAR

13:00–14:00

Hidden No More: Breaking Down Stigmas of HD

Join professionals and advocates, as they answer questions about managing stigmas.

- *Speakers* - Charles Sabine, Dr. Bonnie Hennig-Trestman, Dr. Ferdinando Squitieri, Khadija Chaudhry
- *Room* - Meridian

14:15–14:45

Concurrent Sessions (Choose one of the following)

Family Planning - Explore different options with family planning decisions in HD.

- *Speakers* - Matt Ellison & Jessica Marsolek
- *Room* - Taurus/Aquarius

A Casual Conversation with uniQure

- *Speakers* - Ashley Clarke, Dr. Lauren Byrne, Daniel Leonard & Dr. Bogdan Balas
- *Room* - Zenit

Impacts of Being a Young Caregiver

- *Speaker* - MaryAnn Emerick
- *Room* - Tycho/Kepler

Navigating Relationships (hour-long session) - Learn about how to cope, manage and build relationships.

- *Speaker* - Dr. Kelly Atkins
- *Room* - Nadir

15:00–15:30

Concurrent Sessions (Choose one of the following)

Understanding the Earliest Disease Processes in

Huntington's Disease: Insights from the HD Young Adult Study

- *Speaker* - Dr. Mena Farag
- *Room* - Zenit

Getting Involved - Learn about the many ways to make this community your home.

- *Speaker* - Ashley Clarke
- *Room* - Taurus/Aquarius

Testing Stories: Testing Negative, Positive and the Grey Area (hour-long session)

- *Facilitator* - Dr. Nayana Lahiri
- *Panelists* - Hannah, Wouter, Ashleigh
- *Room* - Tycho/Kepler

Navigating Relationships (hour-long session) - HD impacts every relationship. Learn about how to cope and manage.

- *Speaker* - Dr. Kelly Atkins
- *Room* - Nadir

Juvenile HD Art Session - Open to families impacted by JHD.

- *Facilitators* - Patrick Pollard and Zoe Green
- *Room* - Leo



Saturday

15
MAR

15:45–16:15

Concurrent Sessions (Choose one of the following)

- SKY-0515:** A Daily Pill Designed To Target The Cause Of Huntington's Disease With A Potential To Help Slow Its Progression
- *Speaker - Dr. Meghan Miller (Skyhawk Therapeutics)*
 - *Room - Zenit*

Testing Stories: Testing Negative, Positive and in the Grey Area (hour long session)

- *Facilitator - Dr. Nayana Lahiri*
- *Panelists - Hannah, Wouter, Ashleigh*
- *Room - Tycho/Kepler*

Cultural Exchange: Experiences from across the world (hour long session)

- *Facilitator - Factor-H*
- *Panelists - Juan Carlos, Mustafa, Ana Maria, Ahella*
- *Room - Nadir*

An Open Dialogue on Psychological Support in HD

- *Facilitator - Dr. Nicolò Zarotti*
- *Room - Taurus/Aquarius*

16:30–17:00

Concurrent Sessions (Choose one of the following)

Genetic Modifiers - Dive into somatic instability and other modifiers that could impact HD.

- *Speaker - Dr. Lauren Byrne*
- *Room - Tycho/Kepler*

Speaking to Children About HD:

- *Speaker - Dr. Bonnie Hennig-Trestman*
- *Room - Taurus/Aquarius*

Cultural Exchange: Experiences from across the world (hour long session)

- *Facilitator - Factor-H*
- *Panelists - Juan Carlos, Mustafa, Ana Maria, Ahella*
- *Room - Nadir*

The Power of Collaboration to Advance Research

- *Speakers - Seth Rotberg (Prilenia), Barbara D'Alessio and Michaela Winkleman*
- *Room - Zenit*

17:00–17:30

Concurrent Sessions (Choose one of the following)

Life After Testing Positive

- *Facilitator - Matt Ellison*
- *Panelists - Charlotte, Brianna*
- *Room - Nadir*

Living At Risk

- *Facilitator - Stephanie Carr*
- *Panelists - Nikola, Oviya*
- *Room - Zenit*

Survivor's Guilt

- *Facilitator - MaryAnn Emerick*
- *Panelists - Mackenzie*
- *Room - Tycho/Kepler*



Saturday

15
MAR

19:00–22:00

Let's Dance!

Eat, dance, take photos in the photo booth, chat with exhibitors and more fun! Sponsored by Enroll-HD.

- Rooms - Foyer and Meridian
- The art and writing/chill rooms will also be open.

Each participant 18+ will receive 2 drink tickets to use at the bar. If you are abstaining from alcohol, please let us know at registration. Non alcoholic beverages will be available throughout the evening. Additional alcoholic beverages can be purchased as well.

Sunday

Breakfast will served in the restaurant at the main level of the hotel.

16
MAR

9:00–10:00

HD Buzz Research Breakdown

Learn about past, current and previous clinical trials in HD.

- Speaker - Dr. Rachel Harding
- Room - Meridian

10:00–11:00

Bridging the Gap Between Communities

This is an open discussion between scientists, regulators and the HD community.

- Facilitator - Dr. Ariana Mullin
- Panelists - Astri Arnesen, Lauren Holder, Henk Schuring, Dr. Peter McColgan
- Room - Meridian

11:00–11:15

Break/Exhibit Hall

11:15–12:15

Exhibitor Hall & Lunch (Included with Registration)

Restaurant Veduta on Reception Level; Exhibitors in the Foyer.

12:30–13:30

Observational Studies Dating Game

Meet different observational studies available for the HD community and help ambassadors "swipe right" for which one(s) may work best for them and maybe even you.

- Room - Meridian

13:30–14:30

Keynote: Empowerment through Gratitude

- Speaker - Jimmy Pollard
- Room - Meridian

14:30–15:00

Closing and Awards

- Room - Meridian

Sponsored by

Enroll-HD



Supporting advances in
Huntington's disease research

Proud to partner with HDYO and
the HD community



Thank you for the opportunity
to be part of this important
HDYO event!

We are honored to support and meet
with the HD community as we work
toward a brighter future for those
impacted by Huntington's disease.



Huntington's Disease Patient Advocates,
Brianna (left) and Sarina (right)

022025-NP-GLOB-020



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of **gene therapy**



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www.sparktx.com/contact-us/
for contact information

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Specialty Rooms

Writing/Chill Room

Take a break in this relaxing space to gather your thoughts, journaling and more.

- Room - Virgo

Art Room

Take a break and harness your creative energy with various art projects.

- Room - Leo

These rooms will be available during the conference, including Saturday evening. Please be mindful that people may be processing, or need a quiet space, when entering these rooms.



Get Centered

Enjoy a mid-day break with light yoga, stretching and meditation. No need to change clothes as this will be a low-intensity exercise. Make sure to get lunch afterward.

Saturday, March 15

- Time - 11:40-12:10
- Room - Virgo

Sunday March 16

- Time - 11:10-11:40
- Room - Virgo



On-Site Mental Health Appointments

Visit the HDYO Congress App to schedule an appointment, if you need one-on-one support.

Please note that these professionals will offer advice, but may not be licensed in the Czech Republic.

Direct Contact to HDYO

Visit the HDYO Congress App and message HDYO directly or through WhatsApp.



WAVE™

LIFE SCIENCES

Committed to listening to, learning from, and partnering with the Huntington's disease community

To learn more about Wave and our program, please visit wavelifesciences.com or scan this QR code





Thank You, Sponsors!



Společnost pro pomoc při Huntingtonově chorobě



Scholarship Partners

We are so grateful for our sponsors and partners, for helping provide funds to support young people through scholarships.



Landsforeningen for Huntingtons sykdom



Spoločnosť pre pomoc pri Huntingtonovej chorobe



GOALS

1.

2.

3.

SESSION NOTES

Session Title:

Speaker:

How did you feel?

What did you learn?

Any follow up items when you leave?

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