

2025 Event Schedule



Friday

14
MAR

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| 10:00 | Registration and Exhibit Hall Open |
| 11:00 | First Time Event Attendee/New to HD Meeting |
| 11:00-12:00 | Lunch |
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| 12:15 | Opening Ceremony |
| 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. |
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| 14:30 | Break/Exhibitor Hall |
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| 15:00 | Get To Know Your Table
Make new friends with fun games. |
| 15:30 | Understanding Grief & Loss |
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| 16:00 | Break/Ehibitor Hall |
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| 16:15 | Speed Dating
Get to know other attendees based on similar interests. |
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| 17:30 | Art4HD
Exciting reveal of new mural in Prague about HD.

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

2025 Event Schedule



Saturday

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Breakfast will be served in the restaurant at the main level of the hotel.
Check out Daily Activities for more fun.

9:00

Let's Get Ready for the Day

Review the day

9:05

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*

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*

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

- *Speaker - Jacose Bell (Spark Therapeutics)*

Taking a Whack Out of Mutant Huntingtin

- *Speaker - Dr. Asela Bandara (Wave Life Sciences)*

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

- *Facilitator - Jenna Heilman*
- *Panelists - Meg, Claudia, Joshua*

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)*

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

- *Speaker - Astri Arnesen*

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

- *Facilitator - Jenna Heilman*
- *Panelists - Drake, Francesco, Sharon*

Saturday Continued

2025 Event Schedule



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11:40–12:40

Exhibitor Hall & Lunch (Included with Registration)

Lunch will be held in the restaurant on the main floor of the hotel. Stop by and meet Exhibitors in the Foyer.

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

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

A Casual Conversation with uniQure – Need description

- Speakers – Ashley Clarke, Dr. Lauren Byrne, Daniel Leonar & Dr. Bogdan Balas

Impacts of Being a Young Caregiver – Understand the impact of being a young caregiver.

- Speaker – MaryAnn Emerick

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

- Speaker – Dr. Kelly Atkins

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 (HD-YAS)

- Speaker – Dr. Mena Farag

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

- Speaker – Ashley Clarke

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

- Facilitator – Dr. Nayana Lahiri
- Panelists – Hannah, Wouter and Ashleigh

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

- Speaker – Dr. Kelly Atkins

Saturday Continued

2025 Event Schedule



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15:45-16:15

Concurrent Sessions (Choose one of the following)

An Update from Skyhawk

- Speaker - Dr. Meghan Miller

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

- Facilitator - Dr. Nayana Lahiri
- Panelists - Hannah, Wouter and Ashleigh

Cultural Exchange: Experiences from young people from countries with limited resources, awareness and access. (hour long session)

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

An Open Dialogue on Psychological Support in HD

- Facilitator - Dr. Nicolò Zarotti

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

Speaking to Children About HD:

- Speaker - Dr. Bonnie Hennig-Trestman

Cultural Exchange: Experiences from young people from countries with limited resources, awareness and access. (hour long session)

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

The Power of Collaboration to Advance Research

- Speaker - Seth Rotberg (Prilenia)

17:00-17:30

Concurrent Sessions (Choose one of the following)

Testing Positive - Life between testing and diagnosis

- Facilitator - Matt Ellison
- Panelists - Charlotte, Brianna

Living At Risk

- Facilitator - Stephanie Carr
- Panelists - Nikola, Oviyla

Survivor's Guilt

- Facilitator - MaryAnn Emerick
- Panelists - Mackenzie



Agenda

Saturday, 15 March

Let's Party!

at the Foyer and Ballroom

Let's Party!

Dinner & Dance Party

DJ Dani Cool & Photo Booth

**Saturday, 15 March
7-10 p.m.
Clarion Congress Hotel**

Sponsored By:
Enroll-HD

2025 Event Schedule



Sunday

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9:00–10:00

HD Buzz Research Breakdown

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

- *Speaker - Dr. Rachel Harding*

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*

11:00–11:15

Break

11:15–12:15

Exhibitor Hall & Lunch (Included with Registration)

Lunch will be held in the restaurant on the main floor of the hotel. Stop by and meet Exhibitors in the Foyer.

12:30–13:30

Research Dating Game

Find your match with this interactive “dating” game about current studies in HD.

13:30–2:30

Keynote: Empowerment through Gratitude

Jimmy Pollard

Daily Activities

Daily Morning Activities

Yoga & Meditation Class
Saturday & Sunday - 9 a.m.

Mental Health Support

Art Room and Quiet Area,
Personal Support