



March 17-19 2023
Glasgow, Scotland

Welcome To

HDYO Congress!

We are so thrilled to have each of you in Glasgow for our FIRST IN-PERSON CONGRESS! After canceling our event in 2020, the past few years have been filled with extreme ups and downs. Since announcing this year's event, we have felt this renewed spirit, and resilience in our amazing community.

We are so thankful for the dozens of associations and sponsors who have supported more than 100 scholarships for young people to attend this weekend! We are also grateful for the dozens of volunteers who are here to help.

This event is designed for YOU! We have a variety of sessions based on the interests of young people impacted by Huntington's disease. You can choose what resources will be the most impactful for your needs. We hope you walk away with new friends and feeling empowered to be your own advocate.

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



Jenna Heilman
Executive Director,
HDYO

**Have you downloaded
the Event App, yet?
Visit the HDYO help
booth for more
details.**





Friday



10:00 Registration & Exhibit Hall Open

11:30 Lunch Buffet Open

12:15 Welcome - Main Auditorium

13:30 Exhibit Hall

Ice Breakers - Various Rooms

Get to know others in the community based on common experiences.

14:00 **Part 1:** Gene Positive, Gene Negative, At Risk, Caregiver/Loved One, Professional

15:00 **Part 2:** Regions of the World

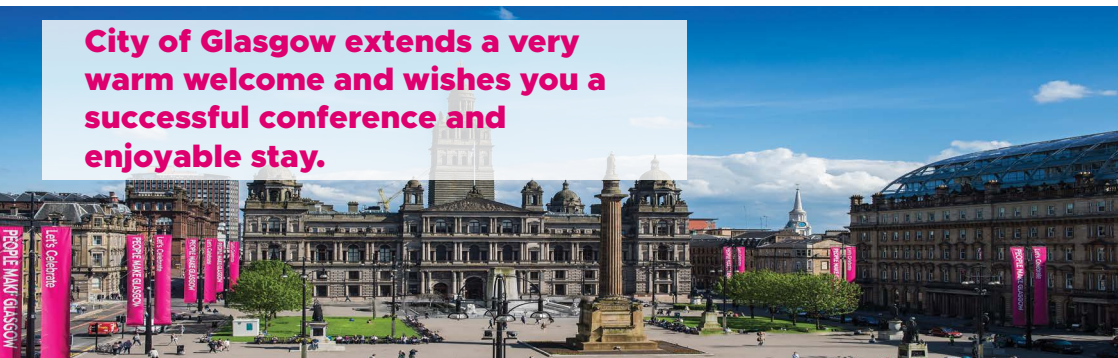
16:00 **Part 3:** Young Caregiver, New to the Community, Parent/Sibling/Partner

17:00 Refresh and walk to the Glasgow Civic Chambers. Each hotel will have an Ambassador to help lead groups. Check Event App for details.

18:00 **Glasgow Civic Welcome**
Join us for a formal welcome from the city leaders.

19:00 **Explore Glasgow for Dinner**
Make a plan with friends to enjoy a dinner at one of the many Glasgow restaurants.

City of Glasgow extends a very warm welcome and wishes you a successful conference and enjoyable stay.



uniQure is committed to the Huntington's Disease community through support of educational conferences like the HDYO annual congress

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Saturday

9:00

Yoga (Conference Room 6-7)

9:00-9:45

HD STRIVE Brainstorming Meeting

For professionals who help support young people & families impacted by HD.

Room: *Conference Room 3*

10:00-10:30

Let's Celebrate Enroll-HD - Main Auditorium

Learn how Enroll-HD has changed the face of research. Join Dr Lauren Byrne, Seth Rotberg, Selene Capodarca & Olivia Handley for a casual conversation.

10:45-11:15

Concurrent Sessions

HD 101 - Learn the basics of Huntington's disease.

Speakers - Dr Hayley Hubberstey & Dr Lauren Byrne

Room - Conference Room 4 & 5

Scientific Update - mRNA Splicing Platforms: Everything You Wanted to Know

Speaker - Amy-Lee Bredlau, MD (PTC Therapeutics)

Room - Level 1 Auditorium

A Personal Perspective - Engaging with the FDA to Start Big Change

Speaker - Seth Rotberg

Room - Main Auditorium

11:20-11:50

Concurrent Sessions

Scientific Update - Gene Therapy - A Closer Look

Speaker - Astrid Valles Sanchez (uniQure)

Room - Level 1 Auditorium

Coping with the Ups & Downs of HD

Speaker - Cat Martin

Room - Main Auditorium



Saturday



Concurrent Sessions Continued

Navigating Relationships - Explore tips on the challenges HD can bring to relationships

Speaker - Dr Kelly Atkins

Room - Conference Room 4 & 5

11:50-12:45

Lunch & Exhibit Hall

12:45-14:15

Ask the Experts Panel - Main Auditorium

From mental health to personal experiences to the latest in science, join HD notable community members to answer your questions.

Panelists - Dr Ed Wild, Dr Bonnie-Hennig-Trestman,

Carly Evans, Matt Ellison, Dr Ferdinando Squitieri,

Astri Arnesen, Dr Olivia Handley & Dr Selene Capodarca

14:30-15:00

Concurrent Sessions

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

Facilitator - Jenna Heilman

Panelists - Charlotte Conn, Mustafa Mehkary & Josefine Harsjo

Room - Level 1 Auditorium

Scientific Update - Huntingtin Lowering: More than one way to peel a banana

Speakers - Dr Ed Wild & Dr Peter McColgan (Roche)

Room - Main Auditorium

Preparing for Genetic Testing

Speakers - MaryAnn Emerick & Jessica Marsolek

Room - Conference Room 4 & 5

Juvenile-onset HD - The Basics of JoHD

Speaker - Dr Oliver Quarrell

Room - Conference Room 3



Saturday

15:15-15:45

Concurrent Sessions

Dual Perspectives Q&A - Continued

Facilitator - Jenna Heilman

Panelists - Paul Conn, Minahil Mehkary & Dennis Hansson

Room - Level 1 Auditorium

Power of Social Media - Learn from Ambassadors how social media can bring awareness and how to safeguard yourself.

Speakers - Ashley Clarke, Charlotte Burke & Robyn Perry

Room - Conference Room 4 & 5

Scientific Update - Looking Back, Looking Forward

Speaker - Andres Cruz-Herranz (Prilenia)

Room - Main Auditorium

Juvenile-onset HD - Family Impact of JoHD

Speaker - Helen Santini

Room - Conference Room 3

16:00-16:30

Concurrent Sessions

Family Planning - Understand some of the options as you may be considering starting a family

Speaker - Dr Kelly Atkins

Room - Level 1 Auditorium

Personal Perspective: Survivor's Guilt - Testing negative can come with a series of emotions. Advocates share their experiences.

Speakers - Jenna Shea, MaryAnn Emerick & Emma Harris

Room - Conference Room 4 & 5



Saturday



Concurrent Sessions Continued

Scientific Update - Allele Selectivity Approach to Lowering Mutant Huntingtin

Speaker - Chelley Casey, Wave Life Sciences

Room - Main Auditorium

Juvenile-onset HD - JOIN-HD & Other Research Opportunities

Speakers - Dr Ferdinando Squitieri & Lauren Byrne

Room - Conference Room 3

14:45-15:15

Concurrent Sessions

Talking to Kids About HD - Many families may have questions or concerns about how to speak to children. We will break down helpful tools.

Speaker - Dr Bonnie Hennig-Trestman

Room - Conference Room 4 & 5

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

Speaker - Corey Janke

Room - Level 1 Auditorium

Getting Involved in the Community - There are many ways that you can become involved. Learn from the experts about their experiences.

Facilitator - Seth Rotberg

Panelists - Erin Paterson, Mustafa Mehkary & Tatiana Santos

Room - Main Auditorium

Juvenile-onset HD - Managing the Many Transitions

Speaker - Helen Santini

Room - Conference Room 3

Saturday, 18 March

Let's Celebrate!

19:00 at the Platform Event Space



Join us for an evening celebration marking 10 years of Enroll-HD!

Platform is a vibrant venue located directly below Glasgow's central station.

Food & Some Beverages Included

253 Argyle St, Glasgow G2 8DL, UK




You Deserve *Brave* Science™

At Neurocrine Biosciences, our purpose is simple: **to relieve suffering for people with great needs, but few options.**

We relentlessly pursue medicines to ease the burden of debilitating diseases and disorders, because **you deserve brave science.**

Visit us at **neurocrine.com**

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Sunday



8:00

Yoga (Conference Room 6 & 7)

9:00-10:00

Research Update with HD Buzz -

Find out the latest in clinical trials.

Speaker - Dr Ed Wild

Room - Main Auditorium

10:00-10:30

Concurrent Sessions

Advocating for the International Community with HD-CAB - Learn about the latest initiative to life international voices to influence research.

Speaker - Astri Arnesen

Room - Main Auditorium

Experiences Participating in Research - This hour-long session will help clarify the experiences of participating in interventional and observational research.

Speakers - Seth Rotberg, Dr Kelly Atkins & Gemma Harverson

Room - Level 1 Auditorium

Professional Experience: Supporting Young People Impacted by HD - Learn from professionals about how they have built their programs, challenges and the need for more support.

Speakers - Grant Walker, James O'Connor & MaryAnn Emerick

Room - Conference Room 4 & 5

10:45-11:15

Concurrent Sessions

Speaking to Strangers About HD - HDYO
Ambassadors share how they confront strangers and even loved ones about HD.

Speakers - Tess Persson, Claudia Villa, Bruce Wilson & Anne Elizabeth Saldarriaga Velez Magnusson

Room - Main Auditorium

Sunday



Concurrent Sessions Continued

Experiences Participating in Research Continued

Room - Level 1 Auditorium

Self-Care Isn't Selfish - This can come in many forms. Learn tips and tools.

Speaker - Dr Bonnie Hennig-Trestman

Room - Conference Room 4 & 5

11:15-12:30

Lunch/Exhibit Hall

12:30-13:00

Awards Ceremony - Main Auditorium

Helpful Information

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 United Kingdom.

Direct Contact to HDYO

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



Other Information

Technology & Innovation Centre
- University of Strathclyde
99 George St, Glasgow G1 1RD,
United Kingdom

Emergency Services

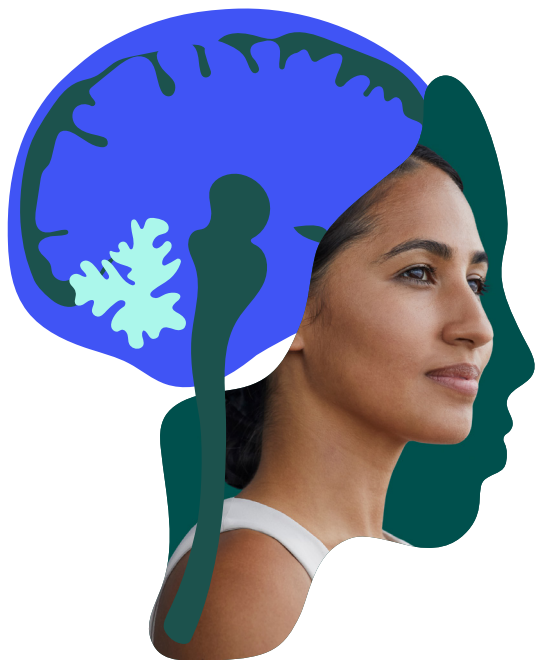
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Committed to listening
to, learning from, and
partnering with the
Huntington's disease
community

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Scholarship Partners

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



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