



Join us on 23 March 2025 for HD Gratitude Day. Find out more in [Dates for Your Diary](#)

## Welcome...

Catherine Deeprouse

Our 54<sup>th</sup> issue of EHDN News brings lots of exciting updates from EHDN and the wider HD community. We are thrilled to share an interview with Patrick Weydt, recently elected Chair of the Executive Committee, and recent developments from EHDN's Imaging Working Group. Read on to find out more about the latest developments in clinical trials, funding opportunities, upcoming conferences, educational courses, and much more.

**-STOP PRESS-**  
**Deep Brain Stimulation against Chorea in HD: Results and Reflections**  
 **WEBINAR**   
**31 March 16:00-17:30 CET.**  
[Join here](#)

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[Catherine Deeprouse](#), Editor  
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## Imaging Working Group: Recent Developments

Nicola Hobbs and Rachael Scahill

The Imaging Working Group (iWG) consists of around 30 researchers from across Europe, Australia and the US, with representation from both academia and industry. As a group, we meet annually to discuss, develop, and promote best practices for the acquisition and analysis of neuroimaging data in HD in a welcoming and inclusive environment. Smaller sub-teams meet more frequently to achieve specific objectives.

Recently, a sub-team composed of both industry and academic experts was formed and tasked with writing a current opinion article on the utility and prospects of including neuroimaging in HD trials. The article, published in the EHDN Corner of the Journal of Huntington's Disease, covers a wide range of imaging modalities, including magnetic resonance imaging (MRI), positron emission tomography (PET), and magnetoencephalography (MEG), and considers several applications from participant selection to demonstration of disease modification. We highlight the huge potential of imaging to facilitate effective clinical trials in HD. However, we also acknowledge the complexities of translating imaging methodologies from observational studies into interventional trials and stress the importance of careful planning and analysis in obtaining reliable imaging readouts. We hope this article will provide a useful resource tool for those planning to include neuroimaging in future HD trials.

Other recent and exciting developments include the launch of our quarterly Imaging Working Group newsletter, spearheaded by Michela Leocadi. The newsletter, available on the EHDN website ([click here](#)), provides updates on key developments in observational and interventional imaging studies, as well as innovations in imaging techniques. The first edition, published in December 2024, showcased research from four



Rachael Scahill and Nicola Hobbs at work

*‘As a group, we meet annually to discuss, develop, and promote best practices for the acquisition and analysis of neuroimaging data in HD in a welcoming and inclusive environment.’*

Nicola Hobbs  
and  
Rachael Scahill



members of the Imaging Working Group: Claudia Metzler-Baddeley (Cardiff University), Marina Papoutsis (IXICO), Eva Woods (Trinity College Dublin) and Mitsuko Nakajima (UCL), and covered multi-shell diffusion analysis using Soma and SANDI, imaging biomarkers as potential surrogate endpoints, neuro-navigated TMS, and quantitative 7T MRI. We look forward to the next edition, which will be released in March 2025. Please do get in touch if you would like to contribute to it ([m.leocadi@ucl.ac.uk](mailto:m.leocadi@ucl.ac.uk)).

We are keen to foster collaborative research with other EHDN working groups. We have expertise across the core imaging modalities, as well as access to longitudinal observational imaging data. If you believe there could be synergy in collaborating to address a specific research question, please get in touch with Nicola Hobbs ([n.hobbs@ucl.ac.uk](mailto:n.hobbs@ucl.ac.uk)) and Rachael Scahill ([r.scahill@ucl.ac.uk](mailto:r.scahill@ucl.ac.uk)). We also welcome new members!

## Update: Clinical Trials

Jenny Townhill and Tim McLean, Central Coordination



Key updates since the last newsletter are provided below for EHDN-endorsed trials and studies; please refer to Table 1 for a summary of all ongoing endorsed research. An expanded description of all EHDN-endorsed trials and studies (completed and in progress), as well as details of the EHDN endorsement process, is published on the [EHDN website](#).

The **Alnylam** sponsored Phase 1b trial testing ALN-HTT02, which targets exon 1 of the HTT gene, started recruitment in November 2024. ALN-HTT02 is a novel C16-siRNA conjugate targeting HTT mRNA and will be tested in approximately 54 participants who will receive a single dose of ALN-HTT02 or placebo via intrathecal

injection. Participants who receive placebo will be given the option to receive ALN-HTT02 during an open-label part of the study. The study is initiating in the UK, Canada and Germany.

**Sage Therapeutics** announced topline results for the Phase 2 12-week DIMENSION study investigating dalzanemdor (SAGE-718) for the treatment of cognitive impairment in HD in November. DIMENSION enrolled 189 participants with HD who were randomised to either dalzanemdor or placebo.

There were no differences found between treatment with dalzanemdor and placebo on the primary clinical endpoint, the Symbol Digit Modalities Test. On this basis, SAGE Therapeutics has decided to cease further development of dalzanemdor, and the ongoing PURVIEW open-label extension study has also been terminated.

**Table 1: Current EHDN Endorsed Trials and Studies**

Registration ID	Sponsor	Trial name	Phase	Investigational Product	Mode of Action	Delivery	Treatment Goal	Target Enrolment	Location(s)	Status
<a href="#">NCT06585449</a>	Alnylam Pharmaceuticals	ALN-HTT02-001	1	ALN-HTT02	Htt lowering; siRNA	Intrathecal	Disease modification	54	Canada, Germany, UK	Recruiting
<a href="#">NCT05541627</a>	BrainVectis, a subsidiary of AskBio	ASK-HD-01-CS-101	1/2	AB-1001	Restoration of cholesterol metabolism dysfunction [AAV delivered gene therapy]	Surgical, intrastriatal	Disease modification	18	France	Active, not recruiting
<a href="#">NCT05686551</a>	Hoffmann-La Roche	GENERATION HD2	2	Tominersen	Htt lowering; ASO	Intrathecal	Disease modification	300	Argentina, Australia, Austria, Canada, Denmark, France, Germany, Italy, New Zealand, Poland, Portugal, Spain, Switzerland, UK, USA	Active, not recruiting
<a href="#">NCT05358717</a>	PTC Therapeutics	PIVOT-HD	2	PTC518	Htt lowering; mRNA splicing modifier	Oral	Disease modification	162	Australia, Austria, Canada, France, Germany, Italy, Netherlands, New Zealand, Spain, UK, USA	Active, not recruiting
<a href="#">NCT05243017</a>	UniQure	HD GeneTRX2	1b/2	AMT-130/rAAV5-miHTT	Htt lowering; miRNA AAV delivered gene therapy	Surgical, intrastriatal	Disease modification	15	Germany, Poland, UK	Active, not recruiting

**Note.** AAV = Adeno-associated virus; ASO = antisense oligonucleotide; Htt = huntingtin; mRNA = messenger ribonucleic acid; OLE = open-label extension; siRNA = small interfering ribonucleic acid

In December, **Roche** announced the completion of recruitment for the GENERATION-HD2 Phase 2 trial of tominersen. The study is designed to follow up all participants for a minimum of 16 months, and is therefore planned to be completed in 2026.

At the Huntington Study Group conference in November 2024, **SOM Biotech** reported results from their Phase 2b trial of SOM3355, bevantolol hydrochloride, targeted at treating chorea. Participants were randomised to receive different doses of SOM3355 or placebo. They found a significant decrease in the Total Maximal Chorea score for people receiving the higher dose of SOM3355 compared with baseline, and there were few side effects. The company now plans to initiate a Phase 3 trial of SOM3355 for HD.

**PTC Therapeutics** reported initial 12-month data from the PIVOT-HD trial of voptoplam (PTC518) in June 2024, showing dose-dependent HTT lowering and a trend towards dose-dependent delay in measures of clinical progression. Final results from the PIVOT-HD trial are expected to be reported in 2Q2025. The 2-year, long-term extension study of voptoplam, PIVOT-LTE is expected to be completed in 2027.

In December, PTC announced a licensing and collaboration agreement with **Novartis**, who will take over the development of voptoplam following completion of the PIVOT-HD trial.

In December, **UniQure** shared key updates from their discussions with the FDA regarding advancing the AMT-130 gene therapy for the treatment of HD. The FDA agreed that the data, shared with them so far from the ongoing Phase I/II studies, compared to a natural history external control, can provide the primary basis for a Biologics Licensing Application for Accelerated Approval.

The FDA also agreed that UniQure may use the cUHRS as an intermediate clinical endpoint for Accelerated Approval and that neurofilament light chain may provide supportive evidence for clinical benefit. Further results from the AMT-130 studies are expected in 2Q2025.

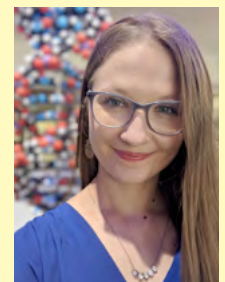
Following the results reported last year by **Wave Life Sciences** from the SELECT-HD trial of WVE-003, an allele-selective antisense oligonucleotide, Wave received encouraging initial feedback from the FDA in November regarding a path to accelerated approval. The FDA were receptive to Wave's plans to assess biomarkers, including caudate atrophy, as endpoints that have the potential to predict clinical benefit. WVE-003 was also granted Orphan Drug Designation. A global phase 2/3 trial of WVE-003 is in planning, with an Investigational New Drug application anticipated to be submitted in the second half of this year.



## Get in touch with the Think Tank!

EHDN's HD Science Think Tank brings together EHDN members and staff who are closely involved in supporting scientific research – including members of the Executive Committee, Central Coordination and the working groups – and it engages with the HD research community in three ways:

- Researchers may contact the Think Tank for help in identifying potential collaborators or funding opportunities, or to discuss scientific ideas
- The Think Tank welcomes suggestions of research topics, and has provided a [contact form](#) on its website via which these can be submitted
- The Think Tank may occasionally propose specific research topics that could be addressed by a dedicated task force working for a defined period of time



**For more information about the Think Tank, please contact [Kinga.Kolodziej@ehdn.org](mailto:Kinga.Kolodziej@ehdn.org)**



Participants can only meet the criteria for one cohort at any given point. During the course of the study, it is expected that participants will transition between cohorts as the disease progresses.

## Update: Enroll-HD: Moving Towards 2.0

Olivia Handley, Enroll-HD Global Platform Manager,  
Selene Capodarca, Enroll-HD Global Study Director,  
Catherine Deeprise

**A major focus for us all is the move towards Enroll-HD 2.0. Planning for this protocol amendment started back in 2023, and preparation took place throughout 2024. Now we are in 2025, we are working hard to ensure that Enroll-HD 2.0 is best placed to build on the tremendous success of the Enroll-HD platform in creating a valuable resource for the entire HD community, including families, clinicians, and researchers.**

### If it isn't broken, why fix it?

As the largest observational study of HD in the world, Enroll-HD has achieved an incredible amount over the past 12 years! Our understanding of HD has significantly improved in this time. Meanwhile, developments in clinical trials have driven a focus on studying participants much earlier in the course of the disease with a view to developing treatments. Enroll-HD 2.0 will continue to help with this by having a strong focus on recruiting participants with HD with no or minimal clinical symptoms (i.e., those in the early stages of the disease) and people at risk of HD.

### How will this be achieved?

In Enroll-HD 2.0, we will aim to recruit and retain a total of 25,000 participants. The study will adopt the recently developed Huntington's Disease Integrated Staging System (HD-ISS; see the [article by Sarah Tabrizi and colleagues](#) published in the *Lancet Neurology*). The HD-ISS is a research framework that aims to harmonise the disease staging of clinical study populations. It is a useful tool that is being incorporated into interventional studies seeking to develop treatments aimed at earlier disease stages.

In Enroll-HD 2.0, participants will be assigned to a specific cohort. The cohort assignment will be based on specific demographics or clinical characteristics.

### Will assessments change?

Following careful scientific review and input, a selection of new and modified assessments have been included in Enroll-HD 2.0. Meanwhile, several assessments from the current protocol have been removed. The battery of assessments will be tailored to each cohort, allowing the utility of the data collected to be maximised. At the same time, the testing burden on participants will be minimised. Enroll-HD 2.0 will also include substudies, including an imaging substudy and the collection of biofluids other than blood (e.g., saliva and tears) at selected sites, which will be optional for participants. Some participants may also be able to complete visits online or by telephone.

### What is happening, and when?

We know it is going to require a substantial and sustained effort over several years to successfully start up each of the Enroll-HD sites (to help put this into context, we currently have 156 active sites!). The good news is that preparations for making the transition to Enroll-HD 2.0 are well underway. The operational infrastructure is undergoing significant modification to be able to support the new features included in the study. This extends to developing new or revised study procedures, training materials, electronic data capture and IT systems, language translations, recruitment materials, acquiring licenses and permissions, revising the study informed consent form, and amending the study site agreement and payment schedule.

A critical aspect of the transition is developing a carefully considered country- and site-level rollout plan. We know the rollout will be executed in phases and will take several years. Each country will be assigned to a given phase based on a number of criteria (e.g., regulatory process, Enroll-HD cohort size). There is a lot of work to be done, but we are steadily making progress in moving towards Enroll-HD 2.0. Watch this space for further updates and developments!

# HDClarity

## Update: HDClarity

Gail Owen, Principal Research Associate, University College London, UK

### Recruitment Status

Since the first cerebral spinal fluid (CSF) samples were collected in 2016, HDClarity has continued to grow, and 2024 was a record year for the study. Last year, 287 CSF samples were collected, meaning that the figure has more than doubled over the last two years. Over 1,000 Enroll-HD participants have volunteered to participate in the study and a quarter of these have provided at least one longitudinal CSF sample. More than 60 participants have contributed three or more samples, providing invaluable longitudinal data.

### Sample Collection

HDClarity sites do an incredible job of recruiting participants – and also much more. When it comes to HDClarity sample collection, sites must coordinate the efforts of several multidisciplinary teams. The PI (or other medic) is responsible for the lumbar puncture procedure used to obtain CSF. They are usually supported by teams from the local clinical research facility, laboratories and Enroll-HD team, including research nurses, laboratory staff, study coordinators and experts in clinical HD ratings. There are at least two study visits during which participant screening and sample collection are carried out, and there is also an optional additional sampling visit. Samples are processed using two centrifuges, an adjustable pipette, a vortex and a -80C freezer, all of which must be calibrated regularly.

### Sample Distribution

HDClarity samples are available to investigators for further research and analysis to help understand HD processes, identify new biomarkers and develop treatments for HD and other neurological conditions. For further information about requesting HDClarity samples for research, please see: <https://enroll-hd.org/for-researchers/access-data-biosamples/>.



### Further information

The current HDClarity protocol and lab manual are available at [www.hdclarity.net](http://www.hdclarity.net), and the UCL Central Coordination team are always happy to answer any questions ([hdclarity-cc@enroll-hd.org](mailto:hdclarity-cc@enroll-hd.org)).

### Interested in Participating?

**Enroll-HD**  [enroll-hd.org](http://enroll-hd.org)

 U.S. National Library of Medicine  
**ClinicalTrials.gov** [clinicaltrials.gov](http://clinicaltrials.gov)

**HDClarity** [hdclarity.net](http://hdclarity.net)

 [@HDClarityStudy](https://twitter.com/HDClarityStudy)

Scan the code for  
more site information:



## Update: Fellowship, Education and Funding

Fionnuala Margreiter, Grants & Collaborations Manager  
Juliana Bronzova, Science Director

### Fellowship Impact Project and HD Workshops: 2024 Highlights

The Fellowship Impact Project concluded in 2024, with the final report now available on the EHDN website <https://ehdn.org/hd-clinicians-researchers/fellowship-programme/>. Insights from the project have already influenced plans for the 2025 fellowship programme. Key findings were presented at major conferences: EHDN & Enroll-HD 2024 (Strasbourg) and Huntington Study Group (Ohio). The project evaluated the programme's impact on continued involvement in HD care as well as past fellows' professional development.

#### 2024 HD workshops by past fellows:

- Armenia (October): International HD experts engaged Armenian and Georgian audiences
- Iran (November): Featured speakers from University College London

These workshops, led by former fellows, demonstrate the programme's ongoing impact in expanding HD knowledge globally.

#### Fellowship Programme

Fellowship placements in 2024 were completed in Spain, Portugal and the UK. Many thanks to the hosts and local clinics for your support of the programme. Fellows appreciated the opportunity to attend the Fellowship Alumni workshop and EHDN & Enroll-HD 2024 meeting, where they connected with the HD research and clinical community. A fellowship alumni group has been formed to encourage collaboration and information sharing.

The application period for the **2025 fellowship programme** closed on 3 February 2025. Applications are now being reviewed, and applicants will



Fionnuala Margreiter



Juliana Bronzova

be informed of the outcome in the coming weeks. EHDN will assist the successful fellows in organising initial contacts with host clinics. If your clinic would like to host a fellow from this programme in the future, please contact us at [fellowship@ehdn.org](mailto:fellowship@ehdn.org).

#### Education Courses

EHDN continues to work closely with the International Parkinson's and Movement Disorders Society (MDS) in organising online courses in HD (as previously held in English and Spanish languages). A follow-up HD course is currently in the initial planning stages with the MDS Pan American group (MDS-PAN). Course directors have been appointed, and course details are currently being decided.

#### EU Grant Application

An EU Marie Curie Doctoral Networks collaborative proposal (*STRIVE HD – STRIatal neuron Vulnerability Evaluation in HD: A bench to bedside training network*) coordinated by EHDN's Science Director, Flaviano Giorgini, was submitted in November 2024. The project application was prepared over several months with collaborative partners from the UK, Spain, Germany, and Italy. If successful, the project will support 15 doctoral positions over 3 years.

**Grant opportunities and updates are regularly shared on the EHDN website and social media. An overview of individual and collaborative grant opportunities can be found at <https://ehdn.org/hd-clinicians-researchers/grant-manager/> as well as some information on the grants and collaboration service.**

## Update: Lesley Jones Seed Funds and Strategic Funding



**William Gray**

**William Gray** at Cardiff University (UK) has been awarded seed funding to support the design of a novel 'tri-cannula' neurosurgical device for convection-enhanced delivery of gene and cell therapies. Despite substantial investment in cell- and gene-therapies for neurological diseases, there are no optimised devices for achieving targeted delivery. Currently, clinical trials use simple scaled-up in-house manufactured or commercial cannulas, which are associated with several drawbacks, including backflow, off-target delivery, and excess cell death. William and the team have developed a prototype design for a device to minimise reflux and shorten operating time, with potential application in both

cell- and gene-therapy delivery. This funding will allow the researchers to undertake additional pump-priming work with material scientists to generate a prototype working device to support funding to take the design forward to a full clinical device.

### Strategic Funding

EHDN is piloting the novel 'Strategic Fund' grant stream for the 1 November 2024 and 1 March 2025 deadlines. Strategic Funding is designed to specifically help Working Groups (WGs) and Task Forces (TFs) achieve their objectives by providing support for discrete projects that align with EHDN strategy. Projects that help build critical mass, collaboration and synergy between WGs/TFs are particularly of particular interest for this funding scheme. The first project to be awarded Strategic Funding was submitted by the Genetic Counselling and Testing WG (Lead Facilitators: Nayana Lahiri and Rhona Macleod) and seeks to review and publish an update to the 2013 International Recommendations for Predictive Test Counselling in Huntington's Disease.



**Flaviano Giorgini**

***The Lesley Jones Seed fund programme is intended to support pilot studies that will eventually kickstart larger projects. The next deadline for applications is 1 November 2025.***



**Kinga Kolodziej**

***More information about the programme and how to apply can be found [here](#) or you can contact Flaviano Giorgini ([flaviano.giorgini@ehdn.org](mailto:flaviano.giorgini@ehdn.org)) or Kinga Kolodziej ([kinga.kolodziej@ehdn.org](mailto:kinga.kolodziej@ehdn.org)) for further information.***



## Update: Staff News



**Adriana Kubis-Kubiak**

On 1 March 2025, **Adriana Kubis-Kubiak** will be joining us as the Lanco for Poland. Adriana holds a PhD in Biochemistry from the University of Wrocław and brings with her over 10 years of experience in pre-clinical toxicology. Welcome to the team!

A full list of EHDN staff can be found at <https://ehdn.org/about-ehdn/ehdn-structure/>. For our latest career opportunities, please see: <https://ehdn.org/about-ehdn/careers/>.

We are sorry to announce that **Katrin Barth** (long standing member of Central Coordination and Language Coordination, and also Enroll-HD Platform IT Director) is leaving her position at EHDN. Katrin explains, 'After nearly two decades as part of the Lanco team and Central Coordination of the EHDN, I find it difficult to express the full depth of my gratitude and affection for this incredible community. I feel honoured to have played a role in establishing the network and watching it grow. Over the years, I have had the privilege of meeting and working with so many dedicated clinicians, scientists, members of HD families, and other supporters. As I step away from this role, I am proud of what has been achieved so far, the collective impact we've had in advancing research and care for HD, and I look forward to seeing how the network will continue to expand and succeed. I cherish the friendships made, the milestones reached, and the inexhaustible commitment of everyone involved. EHDN has been my extended family, and I hope these connections survive the separation.'



**Katrin Barth says farewell**

Thank you for the trust that has been placed in me, the support I have received, and the friendship we have established throughout this journey. I wish each and every one of you success, joy, and continued breakthroughs in the fight against HD. My deep hope is that the structures we have built in the many years can eventually be used to distribute a treatment that slows down the progression of HD. The EHDN spirit will always remain a cherished part of my life. I will certainly miss being part of it.'



## EU Monitoring and EHDN Language Area Coordination Meeting

Catherine Deepprose



**Participants at the EU Monitoring and EHDN Lanco Meeting in Warsaw, Poland**

The most recent EU Monitoring and EHDN Language Area Coordination (Lanco) Meeting took place in Warsaw, Poland, from 22 to 23 January 2025. As always, the team welcomed the opportunity to catch up in person, and hear the latest updates on Enroll-HD, clinical trials, and various EHDN matters. Particular highlights included a presentation from Patrick Weydt sharing insights into EHDN structure and key activities, and a stimulating presentation by Lancos Kerstin Koppers and Eric Decorte on current HD activities in France and Belgium.



## European Huntington Association

Ruth Blanco and Astri Arnesen

A consortium led by the [European Huntington Association](#) and composed of the [Spanish Huntington Association](#) together with the [Ligue Huntington Francophone Belge](#) and [Bulgarian Huntington Association](#) as partner organisations, received an Erasmus+ grant to develop a training project for adults called 'HD Academy'.

The HD Academy will be an innovative, multilingual and inclusive e-learning platform for the free education and training of professionals and formal and informal carers of people impacted by HD. What makes this project truly unique is that the content of the platform is based on the real-life experiences of HD-impacted families and the in-depth knowledge of experts with a long history of HD care that has been gathered through personal interviews.

The online training platform will be available by the end of the first quarter of 2025 and will provide a new online resource available to the global HD



+ Info

[eurohuntington.org](http://eurohuntington.org)  
[astri@eurohuntington.org](mailto:astri@eurohuntington.org)

community. You can find out more at [www.huntington-academy.org](http://www.huntington-academy.org)



## Huntington's Disease Youth Organization

Jenna Heilman

[Huntington's Disease Youth Organization](#) (HDYO) is excited to host the **International Young Adult Congress, 14-16 March, in Prague.**

With an expected attendance of between 300-400 attendees, this will be the largest gathering focused specifically on the experiences and needs of the global community of young people impacted by HD. This is the perfect opportunity for researchers, industry partners, clinicians, and family members who want to better understand this important community. All will be welcome!

**The programme emphasises the three main goals of HDYO: support, educate, and empower**

### FRIDAY: Support

This day will address key areas of making connections with other attendees as well as specific emotional and mental well-being topics. The goal is to allow people to get to know each other while also addressing how to cope, manage and prepare for sessions at Congress. We are also introducing Ambassador buddies to help those who are newer to the community.



Special guests will include the First Lady of the Czech Republic, Czech dancers, a mural reveal from artist [DJLu](#) in partnership with Factor-H, and much more.

### SATURDAY: Education

This day will begin with a session focused on research terminology from Rachel Harding from [HDBuzz](#). In partnership with our Research Committee, we will unveil a printed glossary of relevant terms based on research that is currently being investigated, and participants can follow that as we review those terms and end with an interactive game. The hope is that we break down the barricades of these terms to allow for better understanding of upcoming presentations at Congress and beyond.

Research session will involve the science behind the trials, including topics around endpoints, caudate atrophy, splicing and small molecules, gene therapy, how community feedback impacts research and more.

Other sessions include a Cultural Exchange with [Factor-H](#), Breaking Down Stigmas with a panel of professionals and community members led by Charles Sabine, testing stories featuring people who have tested positive, negative and in the grey area and much more.

We'll end the evening with a party in partnership with [Enroll-HD](#) featuring a DJ, photo booth, food, and more.

### SUNDAY: Empowerment

Rachel will come back to present information on the past, present and future clinical trials.

We will have an open dialogue called Bridging the Gap where we will discuss what's important to the HD community and how that relates to research and bigger advocacy issues.

We will shake it up a bit with the Observational Study Dating Game...curious what that means? Come take a look.

To end the conference, we will welcome Jimmy Pollard, who is creating a new presentation about the power of partnership within the HD community and beyond.



**This event only happens every two years, so don't miss out and register today! More can be found at [hdyocongress.org](https://hdyocongress.org) or by emailing [jenna@hdyo.org](mailto:jenna@hdyo.org).**



## Huntington's Disease Association for England and Wales

Vicki Rutland



### Mental Health and HD

The Huntington's Disease Association for England and Wales has published a report called Unseen and Unheard: The Need to Improve Mental Healthcare for People Living with Huntington's Disease. This report highlights the mental health challenges faced by people living

with HD and sets out recommendations for change. We're calling for people living with HD to have improved support from community mental health services, access to a health or social care professional who is a local expert on their care needs, and investment in specialist mental health support. **You can read the recommendations and the report [here](#).**



### Our Creative Journey

We were delighted to hold an exhibition featuring artwork from members of the Huntington's disease community in the Cotswolds in England. After an online support group call during the COVID-19 lockdown, Carol Dutton, Specialist Adviser for the South West of England, discovered that eight of her group all were creating art as a way to focus. Carol suggested they showcase their work at an exhibition – a project they could all work towards. The exhibition came together in November 2024 and was a great success, with the local press and BBC featuring the story. **You can see some of the amazing work [here](#).**



## Interview with Patrick Weydt: Building on a Critical Mass

With a longstanding commitment to HD research and EHDN, Patrick Weydt was elected Chair of the EHDN Executive Committee in 2024. We spoke with Patrick to find out more about his motivation and background, as well as his vision for the future of HD research.

### How did you get involved in the HD community?

Even as a medical student, I was fascinated by the brain and its diseases. Early in my career, I became interested in amyotrophic lateral sclerosis – ‘ALS’ for short. It was an exciting time, as the first ALS gene and the huntingtin gene were discovered only weeks apart. I clearly recall my first encounter with an individual with HD during an elective abroad in Montreal. He was a very nice man from a large family, and very quickly, the impact of the autosomal pattern of inheritance became evident to me as an impressionable young student.

After completing medical studies in my hometown of Berlin, I started my residency at the University Hospital in Munich. Here, I received a prestigious fellowship to undertake postdoctoral research at the University of Washington in Seattle. This was an incredibly formative and stimulating time: not only did I meet my wonderful wife, but I also started to participate in a tiny but very

dedicated weekly neurodegenerative research journal club – one that included a brilliant fellow postdoc named Flav Giorgini, who was working on yeast genetics at the time. A young principal investigator in that group, Albert La Spada, was already famous for having discovered the first CAG-polyglutamine repeat expansion mutations as a graduate student.

Albert La Spada became a great friend and an important mentor. Together, we obtained a small National Institutes of Health seed fund grant to explore our serendipitous discovery that HD mice have difficulty with temperature regulation resulting from mitochondrial and transcriptional dysregulation. These findings were very well received in the field and helped me to be recognised as a scientist. Metabolic changes in HD were not getting very much attention at the time, but I very much remember being part of a small poster session at a huge neuroscience conference where I hit it off with a fellow young researcher whose poster was right next to mine, and the only other poster on metabolic aspects of HD. That student was Åsa Petersén, from Lund University, who has since become a leader in the HD field as well as a wonderful friend and colleague, and now EHDN Deputy Chair.

*‘I always think the HD community is really special – it stands out across different research fields as being very collaborative and supportive.’*

**Patrick Weydt**

Wanting to continue my clinical training in neurology and having founded a family with my German wife, I was keen to return to Germany. I heard Bernhard Landwehrmeyer present at a Gordon conference, introducing the concept of the European Huntington’s Disease Network. This all seemed very ambitious – but also very exciting. Bernhard is quite a force of nature, and so I took a leap of faith and got involved by joining his clinical group at the University of Ulm. This gave me a ringside seat during the early days of EHDN, even though initially, I was primarily occupied with my residency and my budding family.

I was recruited to Bonn in 2016 as an ALS specialist but negotiated setting up an HD clinic, which was dearly missing there. Now, we have a dedicated clinic that cooperates with the German Center for Neurodegenerative Diseases, where we see around 120 HD-impacted individuals, and just this year, became an Enroll-HD site. Interestingly, I recently discovered that Nora Guthrie – daughter of Woody Guthrie, the American songwriter, musician, writer, and political activist who died with HD in 1967 – also lives nearby some of the time, and she has become very supportive of my centre. Readers may remember Nora from her incredibly inspiring presentation at the 2022 meeting in Bologna. Despite HD being a rare disease, there are many interconnections in this small but hugely critical mass of people.

### How did you get involved with EHDN?

During my time in Ulm, I was nominated to the EHDN Scientific and Bioethics Advisory Committee in 2012 and was elected Chair of this group in 2014. Back then, we didn't have Zoom calls but discussed the funding proposals by phone, so things were very different! It was a tremendously informative and stimulating experience that showed me how rewarding it can be to contribute to the EHDN community. In 2016, just as I was being recruited to Bonn, I decided to run for the EHDN's Executive Committee and was elected at the plenary meeting in The Hague. I was elected Deputy Chair in 2018 and helped Anne Rosser steer the network through the pandemic. I was re-elected to the EC in 2022 and became Chair in 2024, as announced at EHDN & Enroll-HD 2024 in Strasbourg. This was an amazing event, and I really encourage the EHDN membership to become involved in our working groups and committees. It is this membership participation which makes the EHDN such a vital and dynamic organisation.

### What is your vision for the future of EHDN?

One of the greatest strengths of EHDN is that it is a constantly evolving organisation. The mission of EHDN is to advance research, facilitate the conduct of clinical trials, and improve clinical care in HD. An important part of our work is to help provide an infrastructure to allow innovative research and informative clinical trials



Monica Busse, Ed Wild, Åsa Petersen, Patrick Weydt

to be conducted, and another critical component is communicating research results, be they clinical trials, or basic science advances such as somatic instability, to the community. Clinical trials have become, wonderfully, a particularly active area in the HD field. The more results we get, the more complex these results have become, as we have seen in the past few years. Rarely do we see clear yes or no answers but rather complex outcomes that require nuanced interpretation. As an unbiased voice in the field, it is the responsibility of EHDN to share the dissemination and interpretation of these trials appropriately with the HD community and beyond.

*‘As an unbiased voice in the field, it is the responsibility of EHDN to share the dissemination and interpretation of these trials appropriately with the HD community and beyond.’*

Patrick Weydt

### What can you share about the next plenary meeting?

The next plenary meeting will take place in Krakow, Poland, in 2026. There is a lot to look forward to! We have appointed a programme committee, and planning is well underway. We saw in Strasbourg that

integrating the EHDN plenary with the Enroll-HD meeting worked really well, so we are keen to align these meetings again in 2026. We also saw that the updates in clinical trials session was particularly well attended and received, so we are keen to build on the success of that in 2026. Further details about Krakow will be shared in due course, so watch this space!

### What is your motivation in life?

My family is, of course, hugely important to me. We have gone through some terrible hardships together, and this has strengthened us. Gathering strength through hardship is something that I often see in HD families, and it has given me great inspiration. I enjoy travelling and reading, and have recently taken up chess – something which I greatly enjoy but



Patrick Weydt carrying the CAG banner in Bologna 2022

clearly lack talent for! Perhaps lesser known are the facts that I was briefly a child actor and even juggled on national TV! Over the years, I have personally experienced the support that our close-knit HD community provides to everyone. We have a very special community that is not overly driven by personal ambitions but rather by the shared goal of finding an effective treatment for this terrible disease, HD.



## Dates for Your Diary

- **14–16 March 2025:** HDYO's [International Young Adults Congress](#) takes place in Prague, Czech Republic.
- **23 March 2025, 17:00 CET/16:00 GMT/ 12:00 PM EST: HD Gratitude Day.** The third annual day of thanks and celebration will mark the discovery of the HD gene in 1993. The meeting will be hosted by Jimmy Pollard with live presentations from Venezuela, the USA and Europe. All are welcome to [join the zoom meeting here](#).
- **31 March 2025, 16:00–17:30 CET:** EHDN will host a webinar, [Deep Brain Stimulation against Chorea in HD: Results and Reflections](#), chaired by Anne Rosser. The presentation by Jan Vesper will be followed by an expert panel discussion. All are very welcome to attend and ask questions. Please [join the webinar here](#).
- **26–28 June 2025:** The 40<sup>th</sup> [Annual HDSA Convention](#) takes place in Indianapolis, Indiana.
- **15 September 2025:** EHDN Working Group forum. Further details will be announced shortly.
- **25–28 September 2025:** [European Huntington Association 5th Biannual Conference](#) takes place in Bucharest, Romania. The event is aimed at health professionals and families in the HD community. Registration will open in April 2025.
- **11–13 October 2025:** [Huntington's Disease Clinical Research Congress](#) takes place in Nashville, TN, USA. Registration is planned to open in May 2025.
- **1 November 2025:** Closing date for applications to the [EHDN Lesley Jones Seed Fund](#).

Would you like to share an upcoming event with our readers?  
Please email the details to [newsletter@ehdn.org](mailto:newsletter@ehdn.org)

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