



## Welcome...

Catherine Deeprise

Our 57<sup>th</sup> issue of EHDN News brings a wealth of updates from across EHDN and the wider HD community. Highlights include the Path4HD-ISS2 initiative, a multidisciplinary educational course in Latin America, and the latest developments from EHDN-endorsed studies, as well as Enroll-HD and HDClarity. We are also delighted to feature an interview with Nayana Lahiri and Hoa Nguyen, who were elected to EHDN's Executive Committee in 2024. They share insights into their roles and offer an exciting preview of the upcoming EHDN Clinical Research Congress, taking place in Kraków, Poland, 22–24 October 2026.

## Huntington's Gratitude Day: 23 March 2026

Every year, the HD community celebrates and gives thanks for the unique collaboration between HD families, clinicians, and scientists that continues to drive HD science and progress. The date was chosen in recognition of the publication of the landmark paper identifying the gene mutation that causes HD in 1993. This discovery was made possible by the remarkable partnership between committed researchers and the generosity of families in

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Venezuela who donated DNA and detailed medical histories over many years. This partnership continues to inspire the collaborative spirit that defines our community today.

Join this year's worldwide social media campaign by posting your photos from 17 March using

#HDgratitudeday. Don't forget your 'H-Hands' – our universal symbol for Huntington's, Humanity, and Hope.

Contact Jimmy Pollard ([jjpollard@comcast.net](mailto:jjpollard@comcast.net)) with any questions and find out more about Factor-H here: [factor-h.org/](http://factor-h.org/).



*The Path4HD-ISS2WS#1 workshop included representatives from EHDN, CHDI, and academia who engaged in in-depth discussions on trial design, outcome measures, and biomarkers.*

## Path4HD-ISS2 Initiative: Trial Design, Biomarkers, and Outcome Measures in HD

Significant efforts in HD clinical trials are currently focused on disease-modifying approaches in [Huntington's Disease Integrated Staging System \(HD-ISS\) Stage 2](#) and early Stage 3 participants. The HD-ISS is a staging system developed for clinical research, dividing the progression of HD into four distinct stages (see the [November issue of EHDN News](#) for further details). **HD-ISS Stage 2 is critical for drug development because it marks the transition between brain changes and clear clinical symptoms.**

In recognition of this, CHDI and EHDN convened an expert panel (Path4HD-ISS2WS#1) in London from 16 to 17 June 2025 to address fundamental questions about trial design specifically for HD-ISS Stage 2

participants. The workshop included representatives from EHDN, CHDI and academia who engaged in in-depth discussions on trial design, outcome measures, and biomarkers. Following the workshop, a comprehensive report established a shared knowledge base and highlighted key areas for further development.

Building on this, a second workshop (Path4HD-ISS2WS#2) held in Nashville, TN, advanced the discussions with additional input from industry and broader academic representatives. The final report has synthesised expert discussions from the two Path4HD-ISS2 workshops and has integrated them with current regulatory and methodological considerations. Importantly, conclusions highlight gaps, shared priorities, and key next steps for HD clinical trial design, outcome measures, and biomarker strategies. The report will be submitted for publication in a peer-reviewed journal in 2026.



Claudia Perandones

## Advancing Multidisciplinary Education: The EHDN and MDS-PAS Partnership in Latin America

Claudia Perandones, Enroll-HD Regional Director for Latin America, the Iberian Peninsula, and Italy

The complexity of HD demands an approach that transcends the boundaries of a single medical speciality. As professionals dedicated to this pathology, we understand that patient well-being depends on a coordinated network of neurologists, geneticists, therapists, and nutritionists. With this vision, throughout 2025, I had the honour of preparing, coordinating, and participating as a speaker in a series of joint educational courses organised by the EHDN and the International Parkinson and Movement Disorder Society (MDS-PAS), specifically tailored for the Spanish-speaking community.

### A Comprehensive Programme for Real-World Challenges

The course, titled 'Multidisciplinary Management of Huntington's Disease: Present Challenges and Future Perspectives', was structured to address the most critical aspects of the disease, from genetic foundations and differential diagnosis to the latest therapeutic innovations. One of the primary successes of this initiative has been its integration of both pharmacological treatments for motor and non-motor symptoms with the vital role of

non-pharmacological interventions, including physiotherapy, occupational therapy, and the management of speech and swallowing disorders.

### Global Impact and Regional Participation

The regional response was nothing short of extraordinary, demonstrating a profound thirst for specialised knowledge. The course reached a vast and diverse audience, with significant participation from Argentina (119), Mexico (91), Brazil (80), Colombia (63), Peru (53), and Chile (52).

Beyond these major hubs, the programme successfully engaged professionals across the Americas and Europe, including Venezuela, Spain, the USA, Uruguay, Ecuador, Bolivia, and several Central American nations. Truly reflecting its global reach, we were privileged to welcome participants from as far afield as India, Morocco, Romania, Norway, and Switzerland. This diverse attendance served not only as a platform for academic updates but also as a necessary bridge for health centres to engage more actively in international clinical trials and research networks.

*'By standardising knowledge on biomarkers, new therapeutic targets, and integrated care models across so many borders, we are paving the way for more personalised and equitable medicine.'*

Claudia Perandones

### Looking Ahead

The success of these sessions reinforces our conviction that continuous medical education is the most powerful tool for improving patient outcomes. By standardising knowledge on biomarkers, new therapeutic targets, and

integrated care models across so many borders, we are paving the way for more personalised and equitable medicine.

My role as a course director and speaker in this programme has confirmed that there is an unwavering commitment within the international scientific community to lead the change in HD management. We will continue to work so that these educational alliances flourish, ensuring that cutting-edge knowledge reaches every corner of our global network.



**'Multidisciplinary Management of Huntington's Disease: Present Challenges and Future Perspectives' is available in Spanish, free of charge, [registration required](#).**

## AREA4HD International Festival

Selene Capodarca, Co-Founder, That Disorder - Global Human Community

### Bridging Art, Science, and Community in Florence

The AREA4HD International Festival is a first-of-its-kind initiative taking place in Florence, 31 May to 6 June 2026. Organised by [That Disorder - Global Human Community](#), the festival provides a unique international platform where art, science, and community converge and intersect to reframe the narrative of HD. The festival's mission is to replace stigma with a culture of empathy and visibility by leveraging diverse artistic mediums – from photography to dance, modern art, documentaries, and much more.

Throughout the week, the festival will showcase powerful visual narratives, including 'Borderless', a global photographic project by Gabriele Berti highlighting the daily life of families across the world, two photographic exhibitions by [Vladimir Marcano](#) and [Gindel Delgado](#)

depicting the collective resilience and complex realities of families in Venezuela, and '[Hidden World of Huntington's Disease](#)', a collection of photographs from the 'Hidden World of HD' project, sponsored by a team from Edith Cowan University, Perth, using photovoice, a storytelling method where people use photography (photo) and narrative (voice) to share the hidden sides of life with HD. Other projects include:

['Beyond the Frame, Within the Journey'](#): An international photographic contest and exhibition featuring selected works from patients, families, and researchers that document the daily realities and personal challenges and successes of life with a movement disorder. The contest is currently open for submissions, and the prize winners will be announced at the festival.

GLOBAL  
HUMAN  
COMMUNITY  
**THAT  
DISORDER**



*‘The festival’s mission is to replace stigma with a culture of empathy and visibility by leveraging diverse artistic mediums – from photography to dance, modern art, documentaries, and much more.’*

Selene Capodarca

[‘Carolyn’](#) is a photographic project by Nadia Markiewicz documenting a collection of death-related objects assembled by Carolyn Josephine Goracy in the final years of her life, as she approached death from Juvenile HD (JHD). Part of the [LOVE&JHD](#) programme, dedicated to JHD, the project comes from a disabled perspective, situated at the intersection of disability studies and contemporary Gothic aesthetics. The exhibition reframes collecting as a creative and meditative practice through which a person living with a fatal illness engages with mortality as an integrated condition of existence.

The festival concludes on 6 June with a multidisciplinary conference at the **AOU Careggi Hospital** with the participation of local and international professionals, researchers, family members, and associations.

The closing evening, set within the historic [Murate complex](#), will present an exciting range of performances and projections, including live music from Flaviano Giorgini and a live dance piece from the [‘Harmony in](#)

[Disorder’](#) programme specifically portraying the profound impact of HD on intimacy and relationships. This will be accompanied by the documentary [‘L’attesa’ \(Anticipation\)](#), a cross-cultural narrative produced by the association and filmed between Florence and Istanbul and the screening of [‘The Light’](#) by Gindel Delgado, which tells the poignant story of two informal caregivers in Barranquitas, Venezuela.

The association welcomes everyone impacted by or interested in HD to the AREA4HD International Festival. Further information, including registration details, will be published shortly on the association [webpage](#). For any enquiries, email us at [info@thatdisorder.org](mailto:info@thatdisorder.org). Please also get in touch if you are interested in being part of the festival as an artist or collaborating with the association – we would love to hear from you!

## Update: Clinical Trials

Jenny Townhill, EHDN Clinical Trial Director;  
Director, Enroll-HD External Partnerships

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



**uniQure** has continued dialogue with the FDA since the change of stance reported in their November 2025 press release (see the [November issue of EHDN News](#)), with a [Type A meeting scheduled](#) to discuss potential next steps. A further update is expected around March 2026. A recently published article by [HDBuzz](#) provides additional information on the current regulatory situation.

The **Roche** phase 1 POINT-HD trial of the intrathecally administered ASO, RG6496, started recruitment at the end of 2025. The drug targets a specific single nucleotide polymorphism (SNP) on the faulty gene, and therefore only lowers the mutant huntingtin (HTT) protein, leaving the normal HTT intact. Only people with the relevant SNP will

**Table 1: Current EHDN Endorsed Trials**

Registration ID (CT.gov)	Sponsor	Trial name	Phase	Investigational Product	Mode of Action	Delivery	Treatment Goal	Target Enrolment	Location(s)	Status
NCT06585449	Anylam Pharmaceuticals	ALN-HTT02-001	1	ALN-HTT02	HTT lowering; siRNA	Intrathecal	Disease modification	54	Canada, Germany, UK	Recruiting
NCT05686551	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
NCT07246941	Hoffmann-La Roche	POINT-HD	1	RO7764733	mHTT lowering, ASO (SNP directed)	Intrathecal	Disease modification	40		Recruiting
NCT07326709	Novartis Pharmaceuticals	INVEST-HD	3	Votoplam	HTT lowering, splicing modifier	Oral	Disease modification	770	Global	Not yet recruiting
NCT06873334	Skyhawk Therapeutics	FALCON-HD	2/3	SKY-0515	HTT & PMS1 lowering, splicing modifier	Oral	Disease modification		Argentina, Australia, Brazil, Canada, Chile, Colombia, Georgia, Germany, Mexico, New Zealand, Peru, Spain, UK	Recruiting
NCT05243017	uniQure Biopharma B.V.	HD GeneTRX2	1b/2	AMT-130	HTT lowering; miRNA AAV delivered gene therapy	Surgical, intrastriatal	Disease modification	15	Poland, UK	Active, not recruiting
NCT05822908	Vico Therapeutics	VO659-CT01	1/2, open-label	VO659	HTT lowering; allele-preferential ASO	Intrathecal	Disease modification	68 (SCA1, SCA3 and HD)	Denmark, France, Israel, Germany, Netherlands, UK	Recruiting

**Note.** AAV = Adeno-associated virus; ASO = antisense oligonucleotide; HD = Huntington's disease; HTT = huntingtin; mHTT = mutant huntingtin; miRNA = micro ribonucleic acid; PMS1 = postmeiotic segregation increased 1; SCA1 = spinocerebellar ataxia type 1; SCA3 = spinocerebellar ataxia type 3; siRNA = small interfering ribonucleic acid; SNP = single nucleotide polymorphism

be eligible for the study, with approximately 40% of people with HD thought to have it. The study will comprise two parts: part 1 will investigate the safety of various single doses compared to placebo, and part 2 is an open-label extension (OLE) where all eligible participants receive the study drug. See [HDBuzz](#) and [Clinicaltrials.gov](#) for additional information.

**Skyhawk Therapeutics** has recently initiated FALCON-HD, a new worldwide phase 2/3 study of the huntingtin and PMS1 (linked to reduction of somatic expansion of the CAG repeat) lowering splicing modifier, SKY-0515. This trial adds to the portfolio of ongoing studies of SKY-0515, currently in an active treatment extension of a phase 1 trial and a phase 2/3 trial ([Falcon-HD](#)) in Australia and New Zealand.

Interim results from the phase 1 trial were reported in [January 2026](#), with dose-dependent reductions of mutant huntingtin protein of 62% at 9 months (vs baseline) at the highest dose of the two doses tested. A dose-dependent reduction in PMS1 mRNA of 26% was also reported. SKY-0515 was generally well-tolerated at both doses. A pooled analysis of both dose groups was conducted, with a mean improvement for the composite Unified Huntington's Disease Rating Scale (cUHDRS) compared to baseline. At 9 months of treatment, compared with a propensity-weighted external control group derived from Enroll-HD and TRACK-HD data, cUHDRS scores improved by 0.64 points in the treatment group, whereas the control group showed a decline (as expected) of 0.73 points.

**Novartis Pharmaceuticals** has announced further details of the phase 3 trial of voptoplam, INVEST-HD, which will start recruitment this year and enrol 770 participants globally. Participants will be randomised to voptoplam or placebo and have a variable duration of treatment per individual in the double-blind period of the study. The maximum treatment duration will be up to 3 years, as when  $\geq 50\%$  participants complete 3 years of treatment, the double-blind period will end for all participants.

Novartis in-licensed voptoplam from PTC Therapeutics to continue its development following completion of the Phase 2 PIVOT-HD trial. In a recent press release, PTC announced that the FDA has aligned with the proposed phase 3 trial design and is receptive to a potential Accelerated Approval pathway.



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 October 2026**.*



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.*



## Get in Touch with the Think Tank!

EHDN's 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)**



## Update: Enroll-HD

Olivia Handley, Enroll-HD Global Platform Director

**It has been a year since our last formal update, making this a perfect moment to share our progress on the Enroll-HD 2.0 study amendment and to outline what we expect in the year ahead.**

A major milestone this year has been the development of the **Enroll-HD Collaborative Biobank Framework**. This document details how biosamples and data will be stored and distributed. The Framework was submitted to a centralised Institutional Review Board (IRB) and received approval in January 2026. We are integrating the biobank description into the Enroll-HD study protocol (version 2.0) and related documents, including the updated Participant Informed Consent Form.

In parallel to this effort, several new vendors will be working alongside the Enroll-HD team to help support the new features the amendment will bring. For example, there will be a dedicated CRO bringing imaging expertise to support with the iEnroll-HD substudy, and a vendor that specialises in electronic Patient Reported Outcomes (ePRO) platforms so participants can complete ePROs directly into an electronic database via a device such as a tablet or a mobile phone. Participants will be able to complete ePROs either during in-person study visits or remotely beforehand, offering more flexibility and convenience.

Several of the proposed assessments for Enroll-HD 2.0 require new or modified license agreements. Certain assessments (e.g., Patient Reported Outcomes) are not available in every language used in Enroll-HD, so we are in the process of securing permissions to translate, and culturally validate where applicable, those assessments.

Work is underway to build a new electronic data capture (EDC) system that will host Enroll-HD 2.0, its substudies, and nested platform studies such as HDClarity. Our planning also requires a smooth transition of moving sites, participants and relevant data from the



current EDC. Additionally, the new EDC will incorporate new participant cohorts as well as the assessment schedules tailored to each group. It will also feature an expanded range of biological samples to

be collected – this requires updated biokit ordering, tracking of biosample collection, and shipment functionality.

Training will play a crucial role in ensuring a smooth transition to the updated protocol. The approach has been structured into three segments spanning the months before and after the transition of each site. This approach allows Enroll-HD site staff to be trained in a way that maintains quality and also balances the effort required of sites to complete their training alongside other activities relating to the transition. The training structure is planned as follows:

1. **Remote training** (e.g., self-study)
2. **In-person site transition visits**, similar to initiation visits
3. **Follow-up training after the site's transition visit**

Raters will need to be qualified on new and modified assessments, and site teams will be instructed on how each site and existing participants will move into the amended protocol. We are exploring ways to accelerate this process, for example, through the use of AI-based tools.

Looking ahead, we are preparing the **first submission package** for Enroll-HD 2.0. This work includes drafting informed consent templates and assembling supporting documentation. As with any major amendment, timelines for startup can be difficult to predict due to the many moving parts involved. However, we anticipate the next 12 months will be an intensive period of preparation, with the goal of having major infrastructure in place by **early 2027**. The expected timing for site transitions will become clearer once the first IRB submission has been completed.

Together, we look forward to another year of progress as we continue building the foundations for Enroll-HD 2.0.

# HDClarity

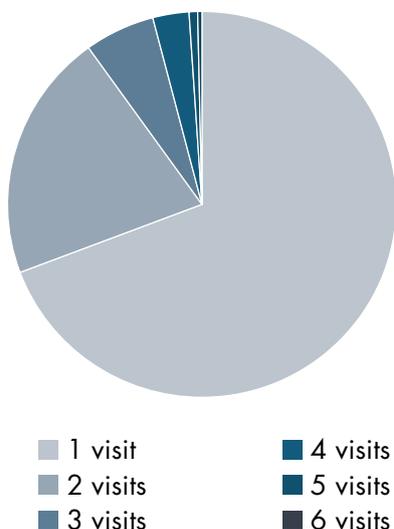
## Update: HDClarity

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

It was a record year for HDClarity in 2025, thanks to our amazing participants and site teams who make the study possible. On average, there were 35 successful cerebrospinal fluid (CSF) and blood collections per month and an amazing 420 in total. Last year also saw the first HDClarity samples collected in France at the Centre Hospitalier Universitaire d’Angers and Le Centre Hospitalier Universitaire de Bordeaux. A new Spanish site also opened in Ramón y Cajal University Hospital in Madrid, and a full list of sites can be found at [www.hdclarity.net](http://www.hdclarity.net).

In total, over 1,200 participants from around the world have contributed to this unique sample repository, and many participants have given samples annually, providing invaluable longitudinal information. Participants consent for four annual visits under the current protocol, but some have already exceeded this by taking part in the study under earlier versions of the protocol!

Longitudinal Participant Visits



### Sample Distribution

HDClarity CSF and blood samples are available to investigators for 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 visit [enroll-hd.org/for-researchers/access-data-biosamples/](http://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)).



## Platform Meeting: Is it time to target inflammation in HD?

EHDN’s first platform meeting of 2026 was dedicated to the role of inflammation in HD, chaired by Maria Björkqvist (Lund University, Sweden). Presenters Roger Barker (University of Cambridge, UK) and Niels Skotte (University of Copenhagen, Denmark) shared insights into their research, followed by an expert panel discussion. Panellists included Mayke Oosterloo (Maastricht University Medical Center, Netherlands), Flaviano Giorgini (University of Leicester, UK), and Carsten Saft (Huntington Centre NRW, Ruhr-University Bochum, Germany). The well-attended meeting concluded with an informative Q&A session. You can find the [recording](#) of the platform meeting (and lots of other exciting content) on EHDN’s [YouTube](#) channel.

## Update: Education and Projects

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

### Fellowship Programme

(written with Asun Martínez)

**If you are working in a region underserved in HD care, expand your clinical expertise through the six-week EHDN–MDS-ES Fellowship Programme! Gain hands-on experience in multidisciplinary HD care at leading European centres, with assistance grants available for fellows. Learn more here: [ehdn.org/hd-clinicians-researchers/fellowship-programme/](https://ehdn.org/hd-clinicians-researchers/fellowship-programme/)**

#### 2026 Fellowship Programme

The 2026 fellowship programme in HD closed for applications in December 2025. Forty-six eligible applications from candidates all over the world were evaluated by EHDN together with MDS-ES. Six applicants were selected for the 2026 fellowship programme, representing Uruguay, Brazil, Nigeria, Argentina, Algeria, and Venezuela.

A pre-fellowship meeting was then organised to introduce the programme to the new fellows, hear about past fellows' experiences and discuss next steps in organising a placement clinic for six weeks. EHDN is assisting in setting up contacts with suitable host clinics and fellowships which will take place during 2026.

#### Hosting of fellows

EHDN sincerely thanks all fellowship hosts and clinics for their dedication and commitment to training colleagues from underserved regions. Your support helps strengthen care, expertise, and awareness of HD across our community. We look forward to welcoming more hosts to join and continue this valuable exchange in future programmes.

Clinics interested in hosting a fellow from this current 2026 programme or for future programmes are invited to register their interest by email to [fellowship@ehdn.org](mailto:fellowship@ehdn.org) and the fellowship team will follow up directly with you.



Fionnuala Margreiter



Juliana Bronzova

#### 2025 programme progress

Five out of six fellows completed their placements in 2025, and feedback from both fellows and hosts was very positive. It also highlighted opportunities to strengthen the programme, e.g., introducing a pre-placement call so fellows better understand the process and encouraging early communication with hosts to discuss expectations, plan ahead, and make the most of the six-week experience.

#### Communication and Education Group News

EHDN is currently undertaking an education project to review and ensure easy accessibility of courses, podcasts, lectures, guidelines, etc., already available on various channels through the work of working groups, task forces, and EHDN. This information has been compiled on a specific webpage on the website: [ehdn.org/about-ehdn/resources-and-services/](https://ehdn.org/about-ehdn/resources-and-services/). Contacts are also being made with other organisations involved in HD courses, information, etc., to ensure that information is shared and communicated to the HD community.

EHDN has recently completed a promotion agreement with the **European Academy of Neurology (EAN)** to promote activities and meetings. EHDN will attend the upcoming EAN Congress in Geneva this year and the EAN will promote the upcoming EHDN Clinical Research Congress 2026 in Kraków, Poland, this October.

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

## Update: Staff News



**Layla Bral**

We are thrilled to welcome Layla Bral (Belgium and the Netherlands Lanco team) to EHDN! Layla joins us with a degree in biomedical sciences, a master's in immunology, and extensive clinical research experience.

A full list of EHDN staff can be found at [ehdn.org/about-ehdn/ehdn-structure/](https://ehdn.org/about-ehdn/ehdn-structure/).



## EU Monitoring and EHDN Language Area Coordination Meeting

The latest EU Monitoring and EHDN Language Area Coordination Meeting took place in Madrid, Spain, 4–5 February 2026. Presentations included the regular updates on Enroll-HD, clinical trials, working groups/task

forces, and other core EHDN activities. Further highlights included an inspiring presentation from Ruth Blanco (Spanish Federation of People Affected by Huntington's Disease) on patient associations and



**Sarah Gunn**

## Wellcome Trust Funding Award to HD Researcher

Congratulations to [Sarah Gunn](#) (University of Leicester, UK) for the award of £1.96 million from the Wellcome Trust to undertake a major research project titled 'Advancing Support and Care for Emotional Needs and Distress in Huntington's Disease' (ASCEND-HD). Building on her established research record in the field, this 8-year project is designed to better understand the impact of HD on psychological well-being and develop new resources for HD-impacted families and healthcare professionals.



## Publication Spotlight

In a timely reflection on humanitarian and care work in Barranquitas, Venezuela, Alex Fisher (Factor-H, University of Birmingham and Birmingham & Solihull Mental Health Foundation Trust, UK) has recently published in the *Journal of Huntington's Disease*. In this fascinating, highly personal account, Alex shares insights into her work with Factor-H and Habitat Luz, improving the lives of families affected by HD in Venezuela against the harsh backdrop of ongoing economic hardship and political upheaval.

collective action in the HD community, and a presentation from Arun Karpur (CHDI) on the applications and contributions of Enroll-HD data to advancing HD science.



We read about Alex's role in establishing the Caregiver's Programme (funded by the prestigious Amgen Prize for Rare Diseases awarded to Factor-H) and the day-to-day, relentless challenges faced by those working on the frontline with Venezuela's neglected families.

### Reference

Fisher A. (2026). The girl at the end of the world - a reflection on humanitarian and care work in Barranquitas, Venezuela. *Journal of Huntington's disease*, [18796397261416568](https://doi.org/10.1080/18796397261416568).



Nayana Lahiri



Hoa Nguyen

## From Strasbourg to Kraków: An Interview with Nayana Lahiri and Hoa Nguyen



### EHDN Clinical Research Congress

Nayana Lahiri (St George's University Hospital, UK) and Hoa Nguyen (Ruhr University Bochum, Germany) were elected to EHDN's [Executive Committee \(EC\)](#) at EHDN & Enroll-HD 2024 in Strasbourg. We caught up with them to hear about their experiences of serving on the EC and leading the EHDN Clinical Research Congress 2026 Programme Committee, and what the community can look forward to in Kraków.

#### What is your background?

**Hoa:** I've been involved in HD research since 1999, and since 2003, I've been working in clinical genetics. I've been at Ruhr University Bochum since 2018, where I am currently Chair of the Department of Human Genetics. We have a large HD centre where I work in diagnostics and counselling with patients while continuing work on a range of research questions, including the mechanisms underlying huntingtin degradation in HD.

**Nayana:** I first started working with HD families in 2007 when I joined Sarah Tabrizi's lab at University College London to work on the TRACK-HD study. After finishing my MD thesis, I returned to Clinical Genetics training and became a consultant at St

George's, where I set up a dedicated HD service. My work is largely clinical, focused on improving care for families, and I'm currently working on international updates to the predictive test recommendations.

#### How did you get involved with EHDN?

**Hoa:** I've been involved right from the very beginning and recall attending the first EHDN meeting just outside Madrid! Over the years, I've been involved in various working groups and, more recently, I've served on the Scientific and Bioethics Advisory Committee reviewing Seed Fund proposals. I was elected to the EC in 2024.

**Nayana:** My first EHDN meeting was in 2008, and like Hoa, I was initially involved in different working groups. Later, I became co-chair of the Genetic Counselling Working Group and was asked to help establish the Incidental Findings Task Force. I have remained involved in various capacities, including serving on the EC since my election in 2024.

*'Being on the EC means being at the forefront of thinking about what matters to HD-affected families and the HD community, and bringing our experiences and opinions to the table collaboratively.'*

Hoa Nguyen

#### What was your motivation for standing for election to the EC?

**Hoa:** EHDN has grown tremendously over the last two decades, and a lot of work goes on behind the scenes. I was really keen to learn more about EHDN's strategy and direction, and to have the opportunity to help shape this. Being on the EC means being at the forefront of thinking about what matters to HD-affected families and the HD

community, and bringing our experiences and opinions to the table collaboratively.

**Nayana:** Having been part of EHDN for so long, it was a huge privilege to stand for election to the EC and to have the opportunity to help shape the future of the organisation. We always say that the HD community embraces researchers, clinicians, and HD families in the shared mission of improving care and advancing HD research. I've gained so much from being part of this community – giving something back by being on the EC is a pleasure.

### What does serving on the programme committee involve?

**Nayana:** Kraków was announced at EHDN & Enroll-HD 2024, and planning started immediately. It's really exciting to embed the work of EHDN with the latest scientific and clinical advances, as well as developments from Enroll-HD. The programme committee is a relatively small group representing EHDN, CHDI, and Enroll-HD, and we have local Polish representation to support planning.

**Hoa:** At this stage, we have developed a preliminary programme. Some details are still in progress, but overall it looks really good. We felt it was important to use our knowledge as clinicians to determine the questions that other clinicians and people impacted by HD will want to hear about.

*'This year's programme will span a very broad range of topics that will hopefully interest everyone in the HD community, including the translation of research findings into the clinic.'*

Hoa Nguyen

### What can we look forward to in Kraków?

**Hoa:** Excitingly, Aaron Ciechanover, the Israeli biologist who shared the 2004 Nobel Prize in Chemistry, will be one of our keynote speakers. He is renowned for his work in characterising the process of protein degradation. This year's programme will span a very broad range of topics that will hopefully interest everyone in the HD community, including the translation of research findings into the clinic.

**Nayana:** We also wanted to place genomics front and centre of the programme. There have been many important advances in recent years, and we've planned a session on how to embed some of them into clinical practice. Another session will look at how best to communicate results and outcomes from clinical trials to the community, a topic of great importance right now. As in previous years, we will also have a range of lively social and networking events, offering many opportunities for delegates to connect with the wider HD community.

#### EHDN Elections 2026:

**Nominations for the Executive Committee (EC) and Scientific and Bioethics Advisory Committee (SBAC) will open in early Spring, followed by the election of the candidates in summer – details to follow. Results will be announced at the EHDN Clinical Research Congress in Kraków.**



## Dates for Your Diary

- **23 March 2026:** HD Gratitude Day
- **29–31 March 2026:** [6<sup>th</sup> RNA Metabolism in Neurological Disease Conference](#) will take place in San Diego, USA.
- **25–27 June 2026:** [41<sup>st</sup> Annual HDSA Convention](#) will take place in Phoenix, AZ.

- **1 October 2026:** Applications for the EHDN [Lesley Jones Seed Fund programme](#) close at 23.59 CET.
- **22–24 October 2026:** EHDN Clinical Research Congress takes place in Kraków, Poland. Further information on registration and abstract submission will be announced shortly.

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