

*In Memoriam  
Dr Ira Shoulson  
1946–2024*



Photo: EHDN

**H**ow do we define a 'life well lived'? While individual perspectives vary, we can probably agree that striving to make the world a better place and leaving a positive impact and legacy are fundamental. There is no doubt that Ira Shoulson achieved all these and much more. We open this edition by reflecting on his life and legacy, taking the opportunity to acknowledge his transformative contributions to HD research and care.

## A Life Well Lived

Catherine Deeprise

On 12 May 2024, the HD community lost a truly pioneering and inspiring figure. Dr Ira Shoulson sadly passed away at the age of 78, having dedicated his life to advancing the understanding and treatment of neurodegenerative and neurogenetic disorders.



**EHDN & Enroll-HD**  
Strasbourg 12–14 Sep 2024

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In 1963, Dr Shoulson started his career at the University of Pennsylvania. He then completed an MD degree and postdoctoral training in medicine and neurology at the University of Rochester, as well as training in experimental therapeutics at the National Institutes of Health.

Driven by insight and compassion, Dr Shoulson's achievements were tremendous. After returning to the University of Rochester, he founded the [Parkinson Study Group](#) in 1985 and the [Huntington Study Group](#) in 1993. Much to his credit, both organisations represent international efforts dedicated to research and treatment development, and remain highly active and influential to this day.



Photo: Private

*‘Losing Ira is so sad. Ira was a true leader and inspiration, and made such a difference to the lives of so many patients and families – he will be very sorely missed. It is a real loss to our community.’*

**Sarah Tabrizi,  
University College London**

There is much that we remain grateful for in commemorating the life of Dr Shoulson. The responses shared by his friends, colleagues, collaborators, and others impacted by his life have been overwhelming both in number and sentiment. On behalf of the EHDN, we join the HD community in sharing our respects and heartfelt recognition of his inspiring life.

*‘I first became aware of Ira at a Huntington’s meeting in the mid-90s, where he was talking about the (then newly created) UHDRS. He was an impressive and energetic figure and has continued since to be a major player in this field. His passing will be a sad loss to the Huntington’s community – clinicians, researchers, and families alike.’*

**Anne Rosser, EHDN Chair**

Dr Shoulson was a key investigator in the landmark US-Venezuela Collaborative Huntington Disease Project, which identified the gene responsible for the hereditary disorder – forever changing the trajectory of HD research. He also developed the Unified Huntington’s Disease Rating Scale (UHDRS), which remains the de facto clinical assessment in HD.

We are deeply saddened by this profound loss but seek comfort in the knowledge that the legacy of Dr Ira Shoulson’s transformative contributions to clinical research in HD and beyond will continue.



Hugh Rickards

## Hosting an EHDN-MDS Clinical Fellow

Hugh Rickards, Birmingham and Solihull Mental Health NHS Foundation Trust, UK

The Birmingham HD team has now hosted a couple of different fellows from overseas, and the experience has been good for both sides. Our team works within a mental health unit, so it was important to make sure the fellows had regular contact with the neurology team, too. From the point of view of the fellows, they really want to see diagnosis, investigation, management, and research in action, so attendance in the clinic is the core of their activity. We also have a community service, so fellows had the opportunity to visit patients and families in their own homes. I think this gave them a really good idea about the cultural context of the disease. They were also exposed to the logistics of service provision (how services were set up and run in the interests of individuals with HD), which hopefully gave them good ideas about how to develop their services when they returned home. We also try to make sure that fellows get to see the whole team at work (not just the clinicians).

From the point of view of the host, we have also gained a lot from the fellowship scheme. It's useful to have to explain to someone else what we do every day – they often have suggestions about how things might be done better. I've also got to know about how healthcare systems work in other countries. As a result of the visit of one fellow, I was able to go and visit them and their team in their home country (Armenia), which included some conference time and general time with the team but also the chance to get to know another country. I went with a friend, and we cycled around the Northern part of the country. Since the visit, we've continued to develop our links with Armenia, including some online tutorials for local residents.

It's been a great experience for me and the team!

***For more details about this ongoing collaboration, see [EHDN/MDS Fellowship Alumna Organises Workshop on HD in this issue.](#)***



## Lancos in Leiden

Maddalena Esteves, Local Area Coordinator (Lanco) for Portugal

Three times per year, all the Lancos across Europe get together. This time, it was in beautiful Leiden, in

the Netherlands, where we were presented with just enough bouts of sunshine for everyone to enjoy the city.

We discussed everything that has been going on with EHDN and Enroll-HD. And it's a lot! There are several programmes continuously on the move, from facilitating the training of young MDs in HD-specialised sites to collaborating with basic and clinical researchers on the lookout for HD answers. And, of course, there is the management of Enroll-HD, with more than 150 sites and 20,000 current participants globally.

The future also promises some exciting times. Enroll-HD is evolving and adapting to the current research needs, and soon, Enroll 2.0 will be ready to launch. Its implementation will be challenging for all the EHDN team, as well as for the sites, but it will be well worth it to attain better data for HD research.

It was also great to see everyone again. These meetings are important in the scientific/operational aspect, but they are also a great way for all of us to reconnect, learn from each other, and overall have some fun together.

*Next stop: Strasbourg!*

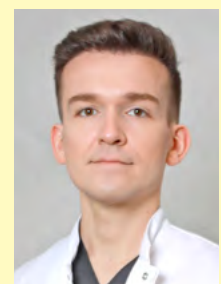


## Get in touch with the Think Tank!

The 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 Yury Seliverstov: [yury.seliverstov@euro-hd.net](mailto:yury.seliverstov@euro-hd.net)**



## Update: Clinical Trial Developments

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 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](#).**

Topline results for the main period of the Prilenia Therapeutics PROOF-HD trial of pridopidine were reported in 2023. Although the primary and secondary endpoints were not met, further pre-specified analyses showed benefit from pridopidine for participants not taking anti-dopaminergic medication.

Participants enrolled in PROOF-HD were offered the option of continuing to receive pridopidine on an open-label basis for up to 12 months. This open-label extension period has been completed, and the study is now closed.

Expanded access/compassionate use programs are ongoing for access to pridopidine for PROOF-HD participants while it remains in clinical development and upon application from qualified physicians (for further information, click [here](#)).

Prilenia is planning to apply to the European Medicines Agency in the coming months for marketing approval. If approved, pridopidine will be commercially available for patients in Europe. Discussions are also planned with the FDA for the USA and will subsequently be considered for other regions.

Sage Therapeutics is investigating dalzanemdor (SAGE-718) for the treatment of cognitive impairment in HD with three parallel studies: the DIMENSION (CIH-201) and SURVEYOR (CIH-202) Phase 2 studies and the PURVIEW (CIH-301) open-label Phase 3 study.

Dalzanemdor has received an Innovation Passport Designation for cognitive impairment associated with HD and entry into the Innovative Licensing and Access Pathway by the UK Medicines and Healthcare Products Regulatory Agency. This pathway aims to accelerate the development time to market and the potential for



Photos: Gabriele Stauner · arifox.com

expedited regulatory review timelines (click [here](#) for further details).

The 28-day SURVEYOR study was completed in April 2024, enrolling 69 participants, and topline data were released on 11 June. The primary endpoint was met, demonstrating a difference in scores on the HD-CAB cognitive assessment battery between healthy participants and participants with HD at baseline. Scores for participants with HD were significantly lower than for healthy controls. There were no new safety concerns and the drug was generally well-tolerated over the treatment period. For additional details, see [here](#).

Results from the 12-week DIMENSION study are expected late this year. The PURVIEW study is enrolling participants who have completed either the SURVEYOR or DIMENSION study and participants who were not in either study. For further details, click [here](#).

The 12-week Phase 2b SOM Biotech trial of SOM3355 (bevantolol hydrochloride) for the treatment of chorea completed recruitment in April 2024, enrolling the target number of 140 participants. Final results are expected towards the end of 2024. SOM3355 is a VMAT2 inhibitor that differs in chemical structure compared to the currently marketed VMAT2 inhibitors for chorea and may have fewer side effects. A previous Phase 1 study of SOM3355 showed that it significantly reduced chorea in patients with HD and was well-tolerated. SOM Biotech plans to consult health regulatory authorities for guidance on a path to marketing approval – click [here](#) for further details.

PTC Therapeutics reported initial 12-month data from the PIVOT-HD trial on 20 June 2024. These interim data confirmed that PTC518 continues to be safe and

well-tolerated, and treatment resulted in dose-dependent mHTT lowering in the blood and cerebrospinal fluid. Early evidence for potential clinical benefits was reported, as demonstrated by favourable trends on

assessments, including the Total Motor Score (TMS) and Composite Unified Huntington's Disease Rating Scale (cUHDRS). For more information, click [here](#).

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

Registration ID (CT.gov)	Sponsor	Trial name	Phase	Investigational Product	Mode of Action	Delivery	Treatment Goal	Target Enrolment	Location(s)	Status
NCT05541627	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
NCT05686551	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	Recruiting
NCT04556656	Prilenia Therapeutics	PROOF-HD	3/OLE*	Pridopidine	Sigma-1 receptor agonist	Oral	Disease modification	480	Austria, Canada, Czech Republic, France, Germany, Italy, Netherlands, Poland, Spain, Switzerland, UK, USA	Completed
NCT05358717	PTC Therapeutics	PIVOT-HD	2	PTC518	mRNA splicing modifier	Oral	Disease modification	162	Australia, Austria, Canada, France, Germany, Italy, Netherlands, New Zealand, Spain, UK, USA	Active, not recruiting
NCT05107128	Sage Therapeutics	DIMENSION	2	SAGE-718	NMDA receptor modulator	Oral	Symptomatic	178	Australia, Canada, UK, USA	Recruiting
NCT05358821	Sage Therapeutics	SURVEYOR	2	SAGE-718	NMDA receptor modulator	Oral	Symptomatic	80	Canada, USA	Completed
NCT05655520	Sage Therapeutics	PURVIEW	3/OLE*	SAGE-718	NMDA receptor modulator	Oral	Symptomatic	300	Australia, Canada, UK, USA	Recruiting
NCT05475483	SOM Biotech	SOMCT03	2b	SOM3355 (bevantolol hydrochloride)	VMAT2 inhibitor	Oral	Symptomatic	129	France, Germany, Italy, Poland, Spain, Switzerland, UK	Active, not recruiting
NCT04120493	UniQure	HD GeneTRX2	1b/2	rAAV5-miHTT	miRNA AAV delivered gene therapy	Surgical, intrastriatal	Disease modification	15	Germany, Poland, UK	Recruiting
NCT05032196	Wave Life Sciences	SELECT-HD	1b/2a	WVE-003	Allele-selective htt lowering ASO	Intrathecal	Disease modification	54	Australia, Canada, France, Germany, Italy, Netherlands, Poland, Spain, Switzerland, UK	Recruiting

**Note.** AAV = Adeno-associated virus; ASO = antisense oligonucleotide; htt = huntingtin; mRNA = messenger ribonucleic acid; NMDA = N-methyl-D-aspartate; OLE = open-label extension; VMAT2 = vesicular monoamine transporter 2

Two further companies are expected to report on data analyses by mid-2024:

- UniQure will provide an update on the HD-GENETRX 1 and 2 gene therapy trials of AMT-130, which will include follow-up data for up to three years on 29 participants. UniQure recently received Regenerative Medicine Advanced Therapy designation from the FDA for AMT-130, which paves the way for accelerated product development and increased collaboration with the FDA for approval planning.

- Wave Life Sciences will report all data from the single-dose cohorts of SELECT-HD and data for the first multiple-dose cohort with extended follow-up.

Currently recruiting endorsed studies include the Roche GENERATION-HD2 trial of tominersen and the UniQure HD-GENETRX trials (the list of participating sites for each study can be found on [clinicaltrials.gov](https://clinicaltrials.gov) and the study record IDs in Table 1).



## Update: Enroll-HD – Recent Additions to Data and Biosamples Collections and Why They Matter

Olivia Handley, Enroll-HD Global Platform Manager, Theresia Kelm, Lanco

Identifying reliable clinical and biological markers in HD will help in understanding the disease mechanisms, monitoring disease onset and progression, and evaluating the efficacy and safety of new treatments. Clinical outcome measures provide quantifiable changes in health, function or quality of life. They may be administered in different forms, for example, patient-reported outcomes (e.g., SF-12v2) or through clinical evaluations (e.g., UHDRS). Biomarkers are indicators of biological processes, pathogenic processes, or responses to an intervention. This article describes examples of how Enroll-HD provides a mechanism to collect high-volume data and biological samples to enable the identification and validation of such clinical outcome measures and blood-based biomarkers.

Demand for specific blood-derived samples, such as plasma and RNA samples in HD research, has increased over recent years. Plasma can be analysed



Photo: Gabriele Stauner - artifax.com

for proteins and other metabolites, while RNA samples help in understanding gene expression patterns. Since the Enroll-HD plasma collection

initiative started in 2019, plasma has been collected from 2,861 Enroll-HD participants from 25 sites in 9 countries and will hit the target of 3,000 over the next few months. The initiative further aims to collect repeat (annual) samples for up to five visits (see Table 2 for the breakdown of longitudinal plasma sample collection).

**Table 2: Participants Per Number of Plasma Visits**

Sum of all participants listed per number of plasma visits	Participants per number of plasma visits				
	One plasma visit	Two plasma visits	Three plasma visits	Four plasma visits	Five plasma visits
2,861	1,105	909	570	225	52

Enroll-HD RNA collection started more recently in February 2024, with the first sample collected at the George Huntington Institute in Germany. Within just a few months, over 100 participants from four Enroll-HD sites have donated samples to the RNA collection. Additional Enroll-HD sites are starting up over the course of the next 12–18 months. Like the plasma initiative, the

overall aim is to follow 3,000 people with HD and approximately 300 control participants for five years.

Clinical outcome measures are complementary tools to biomarkers in clinical research. They provide a measure of how HD and any therapeutic intervention may impact a patient's health and quality of life. The Enroll-HD study has recently expanded its assessment battery to include two new participant-reported outcome measures: FuRST 2.0 and Sleep Assessment.

The FuRST 2.0 is a 24-item assessment designed to be sensitive to functional changes early in HD. Its inclusion in Enroll-HD will enable a better understanding of the natural history and functional impact of HD. The Sleep Assessment includes a 16-item measure composed of the 8-item PROMIS Sleep Disturbance Scale – Short Form 8b and the 8-item PROMIS Sleep-Related Impairment Scale – Short Form 8a. Data from the Sleep Assessment will provide a better understanding of how much sleep disturbance and sleep-related impairment people with HD experience, and how this may change over time in people with HD.

Delivering both assessments through Enroll-HD expedites data collection from a large, well-characterised HD population across many regions. So far, over 150 participants have completed these measures from 12 sites across the USA and Canada. More sites in this region will be joining over the coming months, and as translated and culturally adapted versions of the scales become available over time, more countries will be invited to participate.

Taken together, the initiatives to collect new blood biomarkers and make available new outcome measures illustrate how Enroll-HD continues to be a research platform to expedite our understanding of HD and to support the development of therapeutic interventions.

For further information on how to request data and biosamples for research, please visit [www.enroll-hd.org/for-researchers/access-data-biosamples/](http://www.enroll-hd.org/for-researchers/access-data-biosamples/).





# HDClarity

## Update: HDClarity

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

We would like to introduce one of the highest recruiting HDClarity sites and share some insights into their approach. The Italian League for Research on Huntington (LIRH) Foundation is based in Rome and has been an HDClarity site for over four years. The team recruited their first HDClarity participant in October 2019 – and has since completed more than 80 lumbar punctures! This includes participants recruited under the new HDClarity protocol V4, and the first LIRH longitudinal Year 1 visit is scheduled for this month.

LIRH is a multidisciplinary clinical research team led by Dr Ferdinando Squitieri, composed of neurologists, nurses, biologists, neuropsychologists, and patient advocates, who work together to achieve the study endpoints successfully. The team are dedicated to caring for HD families, and their expertise in HD, combined with constant and transparent communication around research advances, are the key ingredients to their excellent enrollment rate. They are also well supported by the EHDN Language Coordinators and Enroll-HD and HDClarity coordination teams.

When we asked the team about managing HDClarity at LIRH, they told us that it requires challenging organisation and strong collaboration within the team. This extends from a well-organised support team that maintains frequent contact with patients, caregivers, and professionals from multiple disciplines who are highly trained in the study procedures. The team uses many forms of communication, including a website (with 185,000 users in 2023), newsletters, social media, webinars, and an annual LIRH event. They also actively inform participants and their families about HDClarity during their regular Enroll-HD visits.

The LIRH team told us that empathy, trust, and good communication are key when inviting patients to undergo the lumbar puncture without immediate clinical benefit. These efforts are paid back by the appreciation that participants and their families show them and their pride



in participating in this important international research program; they are aware of the importance of actively contributing to finding treatments for HD.

Recently, LIRH opened a new facility (Neurological Rare Disease Centre – CMNR) in Rome. This location is well connected to almost every city in Italy, making it a highly active and successful site. LIRH's original HDClarity site, the CSS Hospital in San Giovanni Rotondo (Southern Italy), also remains active, and the team take pride in offering a double opportunity to families who wish to contribute to HD research.

The LIRH team stresses that people living with HD and their families need help from professionals and advocates to keep trusting in research. This will guarantee the ongoing participation of many in HDClarity and the many other international research initiatives in which they take part. The LIRH motto is 'We care for research, we research with care', and we are so grateful for their amazing contribution to HDClarity!

Further information about HDClarity, including the current protocol, is available at [www.hdclarity.net](http://www.hdclarity.net), and the Central Coordination team are always happy to answer any questions ([hdclarity-cc@enroll-hd.org](mailto:hdclarity-cc@enroll-hd.org)). Information about the study can also be found on a variety of platforms, as shown here.

**Interested in Participating?**



Enroll-HD

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



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: Funding Opportunities

Fionnuala Margreiter, Grants & Collaborations Manager

### Fellowship Impact Project

The EHDN/MD fellowship programme has made significant strides in strengthening clinical care and motivating young professionals. To ensure it continues meeting its key aims of strengthening HD clinical care, facilitating training, and fostering collaboration, the Fellowship Impact Project (FIP) was launched in 2023. Data were collected from past fellows, hosts, and the EHDN organisational support team through surveys and interviews. Many thanks to all the fellows and hosts who gave feedback. We hope to present the results and recommendations arising in a poster at EHDN & Enroll-HD 2024.

### EHDN/MDS Fellowship Alumna Organises Workshop on HD



Photo provided by Zaruhi Tavadyan

**Zaruhi Tavadyan**

Zaruhi Tavadyan, a previous fellow of the EHDN/MDS programme from Armenia, has organised an upcoming workshop on HD. Since her fellowship in Birmingham, UK, hosted by Hugh Rickards (see also his [article in this edition](#)), their collaboration has continued on an

ongoing basis. A two-day workshop dedicated to the aetiology, pathogenesis, genetic basis, and management of HD will take place 19–20 October 2024 in Kotayk, Armenia. The EHDN is happy to continue our ongoing collaboration and to help support this event together with MDS. We look forward to this valuable educational opportunity and to hearing more about it after the event!



Photo: Gabriele Stauner - artfox.com

### Fellowship Workshop at EHDN & Enroll-HD 2024

A workshop dedicated to the EHDN/MDS-ES fellowship programme is planned for EHDN & Enroll-HD 2024. This is a special opportunity for past fellows and hosts to come together, share their experiences, and learn about the results of the FIP. It will be held on 13 September during the lunchtime break. We would like to extend a warm invitation to all past fellows and hosts, as well as any other interested parties, to attend this event. It will be a chance to network and connect with colleagues. We also welcome any brief input from hosts about their experiences in hosting fellows. We are very grateful to the hosts for their ongoing support for the EHDN/MDS fellowship programme, which has made it possible to continue providing valuable opportunities for young clinicians from across the world to learn about HD.

### 2024 Fellowship Applications

A large number of applications were received from around the world and carefully evaluated by EHDN and MDS reviewers. Six fellows were selected, and arrangements for their six-week placement are currently being made with the individual hosts and clinics.

**For regular updates about funding opportunities, please see the [EHDN website](#) and the [Twitter\(X\) account @EHDN GRANTM](#).**

## Update: New Lesley Jones Seed Fund Awarded

The EHDN has recently awarded seed funding for an exciting new project.



Photo provided by Sarah Gunn

**Sarah Gunn**

The EHDN has recently awarded seed funding to [Sarah Gunn](#), [Jane Simpson](#), and [Fiona Eccles](#) for an exciting new project titled **'A qualitative exploration of gaps in mental health support for people affected by Huntington's disease in England and Wales'**.

People who carry the HD gene expansion can experience many mental health difficulties, affecting their quality of life. Unsurprisingly, many people affected by HD consider mental well-being a key issue, but difficulties accessing mental healthcare are common, and evidence is lacking regarding intervention effectiveness. By better understanding the mental well-being needs of people affected by HD and the barriers to good mental healthcare, the researchers will work to generate evidence to improve mental health support.

**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 2024.**



Photo provided by F. Giorgini

**Flaviano Giorgini**

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



Photo provided by K. Kolodziej

**Kinga Kolodziej**



## Physiotherapy Working Group Launches New Resources

Una Jones, EHDN Physiotherapy Working Group Chair



The EHDN Physiotherapy Working Group has proudly launched a new set of resources for healthcare professionals and HD families. These are based on the [physiotherapy guidelines](#) that were published in 2020 and are available on our webpage: <https://ehdn.org/physiotherapy-wg/>. These resources help us achieve our aims of:



- Influencing physiotherapy clinical practice to ensure an internationally consistent approach to the management of problems faced by people with HD through research, and development and implementation of clinical guidelines
- Communicating and collaborating with the HD community to ensure that education and advice are freely available to all

Our group has developed fact sheets on three topics: Exercise and resistance training, Balance and gait training and Cognitive, emotional and behavioural issues. For each topic, there are two fact sheets – one for physiotherapists/healthcare professionals and one for people with HD. We also developed a Residential Care reference guide and are currently co-designing resources for the HD community.

**Look out for us at EHDN & Enroll-HD 2024! If you have any queries about the new resources, please contact Dr Una Jones at [jonesuf@cardiff.ac.uk](mailto:jonesuf@cardiff.ac.uk).**



All Photos: Vladimir Marchano

## EVENT **BEYOND** *the inheritance*

### Beyond the Inheritance (Mas allá de la herencia): A Photo Exhibition by Vladimir Marchano

Selene Capodarca, Claudia Perandones, Ignacio Muñoz-Sanjuan (Factor-H)

Join us at the picturesque Water Castle in Taufkirchen, in the Munich Metropolitan area, for a powerful photo exhibition by the talented Venezuelan photographer Vladimir Marchano.

Through his lens, Vladimir brings together individual stories to create a larger narrative, depicting the complexities and challenges that encompass the lives of individuals affected by HD in Venezuela, offering a profound insight into their reality. Vladimir's photographs not only portray individual struggles but also reveal the collective resilience within the community.

All proceeds from the sale of the photographs will be donated to Factor-H, a non-profit organisation that supports Latin American families affected by HD.



*Water Castle in Taufkirchen (Vils),  
Germany*

The opening takes place  
at 17.00 hours on 17 September 2024.

Attendees will have the opportunity to meet the artist and hear about his work and his collaboration with Factor-H. It is only a few hours from Strasbourg if you are interested in extending your stay in the region.

This exhibition was made possible by the patronage of kbo-Isar-Amper-Klinikum Taufkirchen.

**kbo**  Isar-Amper-Klinikum  
REGION MÜNCHEN  
Zuverlässig an Ihrer Seite

You can find out more about Factor-HD at

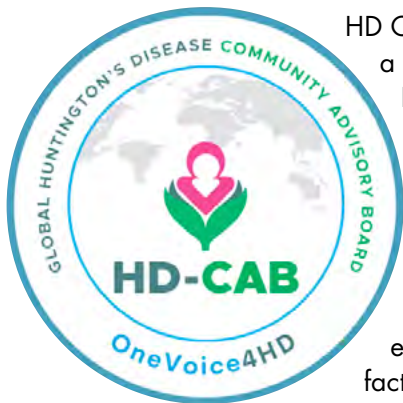
[www.factor-h.org](http://www.factor-h.org).

Additional information about the artist can be found at

[www.vladimirmarchano.com](http://www.vladimirmarchano.com).

## HD Community Ad Board (HD-CAB) Hosts Groundbreaking Discussion

Jenna Heilman, Executive Director,  
[Huntington's Disease Youth Organization](#)



HD Community Ad Board is a partnership between the European Huntington Association, the International Huntington Association, and the Huntington's Disease Youth Organization (HDYO) to ensure that critical factors aren't overlooked in the design and implementation

of clinical trials. We do this by giving a voice to the people who know what it's like to be a trial participant, a potential participant, or a participant partner.

HD-CAB will be hosting a groundbreaking international round table discussion to provide unbiased and equitable access to the HD community to expedite key questions for research. This meeting will be held after EHDN & Enroll-HD 2024 on Sunday, 15 September, at the AC Hotel by Marriott Strasbourg.

As clinical research progresses focusing on preventing or treating HD as early in life as possible, there is a growing need for industry partners, academic researchers, and regulators to rely on the advocacy communities to understand patients' and families' perspectives around these novel therapies and treatment paradigms. In-depth feedback cannot be collected in a simple format like a survey because there is a need to measure the community's understanding around these complex topics first. This forum is intended to engage as many partners as possible at one time on thematic considerations to help industry and research partners further develop studies, trials and advocacy efforts. Follow-up discussions may then be held to focus on specific development programs or therapies.

**For more information, including goals and what to expect, please visit [hd-cab.org](http://hd-cab.org).**



## HDYO International Young Adult Congress

Jenna Heilman, Executive Director,  
[Huntington's Disease Youth Organization](#)

**After a successful first year hosting an in-person event, the HDYO Congress is back! Our next event will be in Prague, 14–16 March 2025.**

This unique event is organised **for young people by young people** and aims to:

- Create a safe place for young people impacted by HD to convene
- Bring young people who haven't spoken about HD before together
- Provide young people with important tools about mental health
- Educate the community on the science behind the trials and studies in HD
- Empower young people through shared experiences to equip them to make decisions
- Connect scientific communities with young people

***This event is for young people, families, those who support young people, and scientific partners who are interested in learning more from this community. Scholarships are also available to bring young people to this event. If you are a potential sponsor, want to help provide scholarships or have any questions, please email [jenna@hdyo.org](mailto:jenna@hdyo.org).***

**More information can be found [here](#).**

## Meet the Candidates for EHDN's Executive Committee

The Executive Committee (EC) governs the EHDN, directs and oversees its activities, and establishes its strategy, as per [Article 4](#) of the EHDN Constitution. Election to the EC offers an exciting opportunity to take on a vital role in shaping the future and direction of the organisation. Voting for candidates opened in early July 2024, and the results will be announced at [EHDN & Enroll 2024](#) in Strasbourg.

A short introduction to each candidate and a summary of their supporting statement are provided below. Regular members of the EHDN members can read the candidate statements in full and cast their vote at <https://www.euro-hd.net/html/network/project/voting> (login required). Voting will close on 11 September 2024.



### Ahmad Aziz

German Center for Neurodegenerative Diseases, Germany

*'In my capacities working with the EHDN, including as chair of the Scientific and Bioethics Advisory Committee, I became convinced*

*of the extremely valuable and important benefits that EC members can offer HD care and research. I hope to continue to contribute to the EHDN's goal of stimulating and fostering innovative and clinically relevant research. My mission is to contribute to a better life for all people living with HD.'*



### Esther Cubo

Hospital Universitario Burgos, Spain

*'My vision is to improve the quality of life of patients and caregivers, and to offer opportunities for young researchers from un-*

*derserved areas to develop their capabilities by creating an international research group. I also hope to promote multidisciplinary care for patients with HD, delivering focused education about HD in medical specialities, including family doctors, medical internists, and allied health professionals.'*



### Huu Phuc Nguyen

University of Tübingen, Germany

*'I am confident that I can help the EHDN define and support research initiatives, as well as contribute to guidelines and*

*recommendations on genetic testing questions in both diagnostic and research contexts. With the genomics era on the horizon, I foresee a need for updated guidelines on diagnostics and novel genetic research directions and that these developments will need to be disseminated in the HD community.'*



### Jaime Kulisevsky

Sant Pau Hospital, Spain

*'The EHDN is well positioned to lead advancements toward effective HD treatments and a cure. I believe my trajectory and insights can offer valuable*

*perspectives, catalysing innovative solutions in our shared mission to alleviate the burden of HD. I humbly offer my candidacy to the EHDN Executive Committee, eager for the opportunity to continue contributing to our community and embarking on a collective journey to combat HD.'*



### Klaus Seppi

Innsbruck Medical University, Austria

*'I would like to see the EHDN pursue a strong partner to shape the future of research and management of HD in a global*

*way with the ultimate goals to improve the care of patients and families, to contribute to the development of a cure for HD and to spread knowledge of HD in the community to increase public awareness of HD. I would like to be a leading part of this mission.'*



### Mayke Oosterloo

Maastricht University and Maastricht University Medical Center, Netherlands

*'I believe I can contribute to the EC on both clinical and scientific topics. As a clinician,*

*I am practical and solution-focused. I like to collaborate with patients, caregivers, and basic scientists,*

and I like to start initiatives and work on several goals in parallel while ensuring success. I believe that these personal characteristics will benefit the work of the EC and help the HD community more generally.'

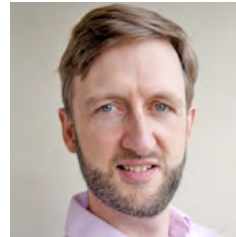


### Nayana Lahiri

St. George's University Hospitals  
NHS Foundation Trust, UK

'I am passionate about the EHDN's mission to advance HD research, conduct clinical trials, and improve care in HD. With

recent advances in genetic modifiers particularly, having Clinical Genetics expertise in the EC will be valuable. However, it is also crucial to maintain a focus on symptomatic management and psychological support for patients and families now whilst preparing for a future with HD-modifying therapies and ensuring access to those therapies. I would bring my expertise as a clinical geneticist who is involved at all stages of the HD patient and family journey.'



### Tom Massey

Cardiff University, UK

'I'm a research Neurologist and currently co-chair the EHDN Genetic Modifiers Working Group and the UK HD network.

The EHDN provides a fantastic continent-wide foundation for HD research and development, but it could be improved further. If elected, I want to do three things: improve support for early-career researchers, embed those with lived experience of HD more into EHDN workflows, and streamline EHDN-linked working groups and structures.'

**'We are thrilled to have such a strong field of nominations for the EC. We encourage all EHDN regular members to take a few moments to read through the candidate statements and vote. Each and every vote really will count, and we value your input in this important process. We look forward to seeing you in Strasbourg for the election results!'**

Anne Rosser and Patrick Weydt



## Dates for your diary

- **29 June to 2 July 2024:** The [10<sup>th</sup> Congress](#) of the [European Academy of Neurology](#) (EAN) takes place in Helsinki, Finland (and online).
- **12–14 September 2024:** [EHDN & Enroll-HD 2024](#) takes place in Strasbourg, France.
- **17–28 September 2024:** Beyond the Inheritance (Mas allá de la herencia): A Photo Exhibition by [Vladimir Marchano](#) will be held in Water Castle at Taufkirchen (Vils), Germany.
- **5–9 October 2024:** The [Society for Neuroscience](#)'s meeting [Neuroscience 2024](#) takes place in Chicago, USA. Registration opens in July – click [here](#) for more details.
- **26–27 October 2024:** The [Huntington's Disease Association](#) will host the Huntington's Disease Community Conference and AGM 2024 in Crewe, UK. Click [here](#) for more information and to register.
- **7–9 November 2024:** [HSG 2024](#), the Annual Meeting of the [Huntington Study Group](#), will take place in person in Cincinnati, USA. Registration is now open.
- **24–27 February 2025:** [CHDI](#)'s 20th Annual HD Therapeutics Conference takes place in Palm Springs, USA. Further details will follow in due course.

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

Follow us on X: @EHDN\_News, and [LinkedIn](#)



# EHDN and Enroll-HD 2024

THURSDAY 12<sup>TH</sup> TO SATURDAY 14<sup>TH</sup> SEPTEMBER, 2024

All sessions are open to clinicians, scientists, HD advocates, and members of families affected by Huntington's disease. Delegates will hear about the latest advances in basic, translational, and clinical research, and meet leading experts in the field.



## Keynote Speakers

- Jean-Louis Mandel (University of Strasbourg)
- Sarah Tabrizi (University College London)
- Harry Orr (University of Minnesota)
- Michael Panzara (Wave Life Sciences)



## Special Talks

- Charles Sabine (Hidden No More Foundation)
- Dimitri Poffé (HD advocate)
- G. Bernhard Landwehrmeyer (Ulm University)
- Patrik Bundin (F. Hoffmann-La Roche)
- Anne Rosser (Cardiff University)



## Poster Presentations



## Movie Night



## Parallel Sessions

- Disease mechanisms
- Biomarkers
- Therapeutic targets
- Genetic Modifiers
- Cognition
- Metabolic dysfunction
- Palliative care
- Occupational therapy
- Clinical studies

## ENROLL-HD

- Enroll-HD 2.0
- Huntington's Disease Integrated Staging System
- Best practice in study coordination

## CONTACT:

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Find more information here:

[ehdn.org/ehdn2024](http://ehdn.org/ehdn2024)

or scan QR-code ->

