

Welcome...

Our 55th issue of EHDN News opens with a tribute to our much-loved and sadly missed colleague, Tim McLean. Highlights include a call to action from EHDN's HEATED task force, updates on clinical trials, and an interview with Daniel Claassen, newly appointed Chief Executive Officer at the Huntington Study Group.

Catherine Deepprose, Editor



Tim at the EHDN Plenary Meeting in Bologna, 2022

Remembering the Life of Tim McLean

(5 June 1958 – 31 March 2025)

Tim McLean, our wonderful colleague and dear friend, sadly passed away on 31 March this year following a short illness.

In the sixth year after the conception of EHDN, the organisation had matured enough to hire a seasoned manager to oversee its clinical activities. As Bernhard Landwehrmeyer recalls, the EHDN leadership team at the time interviewed several candidates. After meeting Tim, there were no questions about who should be offered the position. Bernhard comments, 'We were very fortunate at the time to convince Tim to join EHDN as Clinical Operations Manager'. A core responsibility of this role included overseeing

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operational support for EHDN-endorsed clinical trials and observational studies. Tim was also an ex officio member of the Executive Committee and Co-Leader of the Enroll-HD Clinical Platform.

The nature of this position, along with Tim's open and friendly nature, meant that he interacted with many people across EHDN, Enroll-HD, and beyond. Joining EHDN also worked for Tim – he often said that his time within the HD community was a highlight of his career and that he felt privileged to be able to contribute and work with so many dedicated and passionate people. Jenny Townhill, who worked closely with Tim, speaks for us all in explaining that, without a doubt, the privilege was ours.

Tim had a tremendous work ethic, excelled at his job, and could be relied on to quickly sense what was needed in any particular situation. A particular gift was his ability to approach challenges calmly and methodically. Tim was genuinely interested in other people and always willing to listen. He also possessed a keen sense of humour, even in the face of occasional frustrations.

EHDN Chair Patrick Weydt recalls that when he became Deputy Chair in 2018, Tim provided valuable mentorship and remained a trusted advisor and sounding board through-out their time together on the Executive Committee.



Tim at the EHDN Plenary Meeting in Vienna, 2018

When illness struck, Tim showed extraordinary grace and self-possession. Longstanding friend and colleague Anne Rosser notes that Tim didn't show signs of anger or look for sympathy but wanted to continue working and to keep things as normal as possible. Tim was characteristically conscientious in ensuring his work was wrapped up and entrusted to colleagues as his illness progressed. As such, he lived the last few months as fully as he could.

When the news of his passing spread throughout the HD community, we were quickly met with condolences and expressions of sadness from friends, colleagues, and former colleagues across the world, serving as an unwavering testament to his impact.

We were privileged to have the opportunity to celebrate Tim's life with some of his family in Edinburgh in May. It was fitting to meet at Tim's favourite local venue for food and drinks, with live music by EHDN's Flav Giorgini, to share our personal memories and bittersweet reflections on Tim's unique and unforgettable contributions.

We continue to miss Tim tremendously and remain thankful for our memories and his remarkable legacy of wisdom, warmth, and kindness.



Tim chairing a session at EHDN & Enroll-HD 2024 in Strasbourg



Jamie Levey and Flav Giorgini led the tributes to Tim in Edinburgh

The HEATED (Huntington's Equal Access to Effective Drugs) Task Force

Hugh Rickards, Lead Facilitator

EHDN's HEATED task force was initiated in 2018. It was prompted by the initial successes of tominersen and led to the question – 'What does success look like in HD treatment?' Some aspects of this question are easy to answer. A successful treatment would modify the faulty biological processes associated with HD to reduce the toxic effects on brain cells. A successful treatment would also make a meaningful impact on the lives of people with HD and their families. Ideally, this should also happen as quickly as possible. I think the global HD community is making fantastic progress on most of the above. However, there is an additional success criterion that is relatively neglected: a treatment can only be successful if it is available to as many people as possible who could benefit from it.

The HEATED task force was established to specifically look at this issue, identify potential barriers to accessible treatments, and work towards overcoming them. Any effective drugs will have to be licenced, paid for, and delivered. These are significant hurdles that vary greatly between and within countries.

Licensing is perhaps the 'easiest' of the three barriers. A licence allows a country to produce and market a drug within its borders. To be licenced, a drug must be broadly safe and show some beneficial effect on the lives of patients.

Paying for new drugs is complicated and varies depending on the country and its healthcare system. We have very little expertise in the HD community to help us influence payment processes – and an effective HD drug is likely to be expensive. This means we have to organise ourselves to better understand how funding decisions are made.

Finally, there are **access** challenges arising from the complicated drug administration of these therapies to people with HD. This varies significantly depending on the mode of delivery (for instance, a tablet, an IV, an intrathecal infusion, or an infusion directly into the brain). Some of these methods will require hospitals



*Hugh Rickards, lead facilitator
of the HEATED task force*

to provide additional infrastructure and staff, which again will need to be funded. Depending on the country, these required resources may be barriers to treatment, even for approved therapies, which will again need to be funded.

Our research community has been fantastic in exploring the biology of HD and finding ways to fix the faulty biological processes. However, the next steps will require a range of non-biology skills, such as those of experts in health policy, pharmaceutical companies, health structures, and health economics, whom we have not been engaging in these conversations. We must also include the global HD community in advocating for access to these treatments. There are many examples in healthcare where a well-organised community can have a positive and significant impact on decision-making – consider the success of ensuring access to drugs in fields such as HIV and spinal muscular atrophy.

Will you be a part of the solution? We are actively recruiting passionate 'doers' who don't necessarily need expert skills in access (although these are always useful), just a willingness to learn and engage with the problems.

If you are interested in the HEATED task force, please email me at hugh.rickards@nhs.net.



That Disorder – Global Human Community

That Disorder – Global Human Community is a newly born association led by Gabriele Berti (President), Selene Capodarca (Vice President and EHDN's Enroll-HD Global Study Director), Giovanni Cancellieri (Advisor), and Camilla Ferrari (Scientific Director). The association uses art as a powerful tool to raise awareness about HD, combat stigma, and drive social change. The HD community is characterised by the spirit of human connection, exchange, and collaboration, and this underpins the ethos of That Disorder. Selene shares that their association has been met with incredible enthusiasm, both in Italy and internationally, from individuals, professionals, and organisations wanting to get involved.

The first artistic project, *Borderless*, was initiated in 2024 by Gabriele as a worldwide photographic venture illustrating the daily challenges faced by families impacted by HD. It has already been launched in Pakistan, Mexico, Romania, Spain, and Portugal, and the team is now seeking to expand it to as many countries as possible. Families interested in participating are warmly invited to get in touch (details below).

Other artistic projects include *Harmony in Disorder*, a poignant and captivating dance performance series directed by Maher Shamsamreh (Director of the Orient & Dance Theater in Ramallah) that offers a different narrative about HD. The [first performance](#) was dedicated to the figure of the caregiver and portrayed a story of challenge and support. A documentary about the performance will be screened at the [Awladna](#) International Forum for Arts and Gifted in Cairo in September 2025.

‘The HD community is characterised by the spirit of human connection, exchange, and collaboration, and this underpins the ethos of That Disorder.’



That Disorder - Global Human Community works to raise awareness about HD, combat stigma, and drive social change. Credit: Gabriele Berti.

The team is also developing a series of documentaries that will explore the diverse realities of living with HD, and they welcome input from interested readers. The documentaries will cover topics such as genetic testing, reproductive choices, the vital role of caregivers, navigating end-of-life decisions, and the challenges encountered at various stages of the disease.

The association is also participating in the [Hidden World of Huntington's Disease](#) project run by the Centre for Precision Health at Edith Cowan University in Perth, Australia. The project utilises photography to share the often hidden aspects of life with HD and is open to people with HD, their families, caregivers, health professionals, and researchers. A pilot study is underway in collaboration with [Huntington's Australia](#).

Gabriele, Selene, and the team are also keen to make a concrete, practical difference through a series of programmes conducted in collaboration with health and other professionals. *HDental*, a project led by Giovanni, provides much-needed dental care to people affected by HD and educates caregivers on

proper oral hygiene practices. This project is currently running in Italy and is being expanded in collaboration with the [Factor-H](#) team of specialists in Venezuela to Barranquitas and San Luis. These priority action areas have the highest prevalence of HD in the world. The initiative will promote the exchange of knowledge and



Aida, a young Spanish girl from Córdoba, who participated in the Borderless project. Credit: Gabriele Berti

experiences, and Giovanni will contribute by leading workshops for young dentist volunteers and caregivers.

A dance therapy project is being launched in collaboration with the Huntington Center of the Isar Amper Klinikum, led by Alzbeta Mühlbäck. The project features a dance therapy workshop that includes both people with HD and local professionals. International professionals seeking to enhance their knowledge about dance therapy and implement it in their own clinics are also encouraged to get involved!

A further collaboration is underway with the University of Florence's Department of Motor Sciences. This project

is implementing exercise protocols based on current research to improve the quality of life of people with HD by enhancing coordination, balance, strength, and overall motor function. Beyond the direct benefits for participants, the partnership will also contribute valuable data to scientific research. That Disorder is also hosting Awareness Walks in Florence, which increase awareness about HD, foster a sense of community by connecting families, and promote socialisation.



HDental provides dental care to people affected by HD and educates caregivers. Credit: Gabriele Berti.

If you would like to find out more, please visit thatdisorder.org, follow That Disorder on [Facebook](#), or get in touch via email at info@thatdisorder.org.



Huntington's Disease Association

Vicki Rutland

[HDYES \(Huntington's Disease Youth Engagement Service\)](#) is a three-year England-wide project, part-funded by The National Lottery Community Fund. Now in its second year, HDYES has continued to transform the lives of children and young people affected by HD. A recent evaluation confirms that the project increases knowledge, reduces isolation, builds resilience, and helps prepare young people for the future.

A standout achievement is the ongoing success of HD Youth Voice, a leadership group of 17 young people aged 16–27 who co-produce resources, run peer support sessions, and influence national awareness campaigns. Highlights include the creation of the HD Passport, which enables young people to share their needs with schools and employers, and the award-nominated '[You Are Not Alone](#)' film.

Update: Clinical Trials

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

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) and details of the EHDN endorsement process are published on the [EHDN website](#).

uniQure [announced](#) in April that its gene therapy drug AMT-130 was granted [Breakthrough Therapy designation](#) by the US regulatory agency, the FDA. This designation is given to drugs where there is preliminary clinical evidence that indicates potential for substantial improvement on clinically significant endpoints compared to available treatments. Having this designation gives a company access to additional resources from the FDA, including intensive guidance on the drug development pathway and other activities that may facilitate and expedite review.



The Breakthrough Therapy designation was supported by data from the ongoing Phase 1/2 studies, which, when compared to a statistically-matched natural history external control group, showed dose-dependent slowing in disease progression as measured by the composite Unified Huntington's Disease Rating Scale (cUHDRS) and a significant reduction in neurofilament light chain protein (NfL; a biomarker for neurodegeneration in HD) at 24 months. uniQure previously [shared](#) that the FDA agreed that these clinical data can provide the primary basis for a Biologics Licensing Application (BLA) for Accelerated Approval, with the cUHDRS as an intermediate clinical endpoint and that NfL may provide supportive evidence for clinical benefit.

On 2 June, uniQure [announced](#) that following a recent meeting with the FDA, the agency continued to be supportive of the cUHDRS as an acceptable registrational intermediate clinical endpoint. In addition, the FDA agreed that the primary efficacy analysis for the BLA can be based on 3-year data from the high-dose AMT-130 group compared to a matched external control group,

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
NCT06585449	Alnylam 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
NCT05358717	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
NCT05243017	UniQure	HD GeneTRX2	1b/2	AMT-130	Htt lowering; miRNA AAV delivered gene therapy	Surgical, intrastriatal	Disease modification	15	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

and that a dataset from the Enroll-HD study is acceptable for the primary analysis. Additional analyses using the TRACK-HD/TRACK-ON and PREDICT-HD datasets will also be submitted. An update from uniQure on 3-year topline data is expected in the third quarter of 2025.

Roche provided an [update](#) on the ongoing GENERATION-HD2 phase 2 trial of tominersen in April, following a planned interim data analysis reviewed by an independent data monitoring committee (iDMC). The study was testing two dose levels of tominersen (100 mg and 60 mg) compared with placebo and completed enrollment of 301 participants in January 2025.

After reviewing safety data, the iDMC recommended that the study continue, and there were no concerns with either dose of tominersen. However, there was a greater likelihood of clinical benefit with the 100 mg dose compared to the 60 mg dose, and therefore, the 60 mg dose has been discontinued.

The study has been amended, and participants who were receiving the 60 mg dose will now continue on the 100 mg dose for the remainder of the study. Participants already receiving the 100 mg dose or placebo will remain in these groups. The study is expected to be completed in 2026, and the iDMC will continue to review the data every 4 to 6 months. In May, **PTC Therapeutics** reported [topline results](#) from the Phase 2 PIVOT-HD trial of its splicing modifier drug vutoplam (PTC518). The trial enrolled 159 participants stratified using the Huntington's Disease Integrated Staging System (HD-ISS), 81 stage 2 and 78 stage 3 participants, and compared two doses of vutoplam with placebo.

The primary endpoint, reduction in blood huntingtin (HTT) protein at 12 weeks, was met and also maintained at 12 months. The larger dose of the drug led to greater HTT reduction: 23% at the 5 mg dose for stage 2 and stage 3 participants, and 39% (stage 2 participants) and 36% (stage 3 participants) at the 10 mg dose. Importantly, there were no safety concerns, with no serious adverse events related to treatment or any spikes in NFL.

For stage 2 participants, there were favourable dose-dependent trends on the cUHDS and Total Functional Capacity (TFC) clinical assessments. For stage 3 participants, positive trends were only observed in the 5 mg dose group compared with the placebo group.

The company also reported data on 21 participants who have 24-month data from the PIVOT-LTE extension study. Signs of dose-dependent trends were observed on the cUHDS, TFC, and Symbol Digit Modalities Test in comparison to a statistically-matched cohort from the Enroll-HD study. For additional discussion of these results, see the [recent post](#) by HDBuzz. **Novartis** is now expected to continue the development of vutoplam.



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





Update: Enroll-HD Datasets and Biosamples

Olivia Handley, Enroll-HD Global Platform Director

One of the core features of the Enroll-HD Platform is the release of comprehensive datasets to the research community every 1–2 years – these are known as **periodic datasets** or ‘PDS’ releases. Additionally, specified datasets and biosamples can be made available to researchers on request. These datasets have contributed to [over 160 peer-reviewed publications](#) to date.

What do periodic datasets contain?

While each PDS provides a rich resource for HD research, it does not include all data collected in the Enroll-HD study. For example, individual items from certain assessment data are not included, and other data that could be potentially identifying (e.g., larger allele lengths above a certain cut-off) are only available as aggregated values. For researchers needing access to more specific data elements, a **Specified Dataset** (‘SPS’) request can be submitted at any time. Such requests for data may require review by the Enroll-HD Scientific Review Committee (SRC).

The seventh PDS release is scheduled for later this year, with more participants and study visits than ever before – final figures are in preparation! Each PDS release is accompanied by supporting documents designed to describe, explain, and assist end users in working with the data. Anyone interested and/or in receipt of the PDS is encouraged to review these documents, which are available on the [Documentation](#) page of the Enroll-HD website.

What additional data are available?

Alongside the datasets, Enroll-HD has a well-established biosamples repository that includes:

- Whole blood DNA
- Peripheral blood mononuclear cells
- EDTA plasma
- RNA PaxGene
- Lymphoblastoid cell lines
- DNA from Lymphoblastoid Cell Lines



Biosample requests can also be submitted at any time. Requests for non-renewable biosamples are submitted to the Enroll-HD SRC for review.

How do researchers access data?

Researchers at a recognised research organisation can request data and/or biosamples and will require institutional authorisation to sign data and/or biosample use agreements. For further information on what is required to access data and biosamples, please visit enroll-hd.org/for-researchers/access-data-biosamples/.

The Enroll-HD request form has recently been updated to make it more user-friendly for requestors, SRC reviewers, and the operations team that coordinates and delivers requests. A future goal is to host the request and distribution process entirely online to streamline the process further.

What is the cost to researchers?

Enroll-HD PDS releases and SPS datasets are made available free of charge. However, there is inevitably a cost associated with biosamples requests that includes biosample, shipping, and handling fees. An overview of costs per biosample type is available on the [Enroll-HD website](#).

Further information for researchers on how to request data generated from Enroll-HD is available on the Enroll-HD website:

- Enroll-HD [Access](#) page
- Enroll-HD [publication policy](#)

Thanks to Christine Capper-Loup for her review of this article.

HDClarity

Update: HDClarity

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

HDClarity aims to generate a high-quality, longitudinal collection of cerebrospinal fluid (CSF) and plasma samples from 2,500 participants enrolled in the Enroll-HD study.

HDClarity currently has **37** active sites across **nine** countries worldwide. A total of **1,090** unique participants have successfully completed at least one sampling visit. As of 1 June, a total of **174** CSF samples have been collected in 2025.

As the largest longitudinal collection of high-quality CSF and blood ever assembled in HD, HDClarity will enable a new generation of innovative scientific projects at a critical time for the development of novel therapeutics.

HDClarity PDS3 contains data from 673 study participants and includes 832 study visit packages, each associated with one or more successfully collected CSF samples. A summary of each PDS released is shown in Figure 1 below.

The HDClarity PDS3 and associated biosamples are made available through the Enroll-HD platform. To access these resources, please visit the Access page on the Enroll-HD website.

HDClarity PDS4 will be available later in 2025, and it will contain data from more than 1,000 participants!



Figure 1. HDClarity sample size by PDS release.

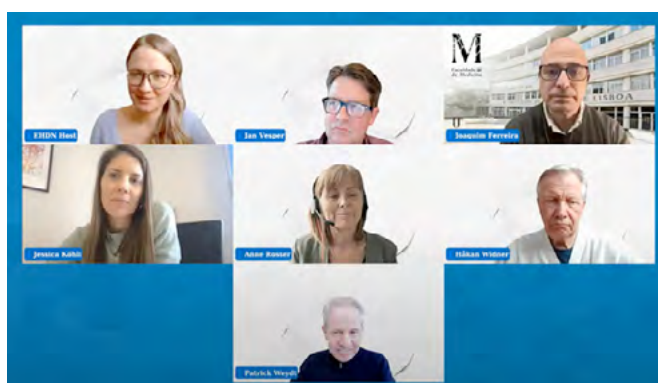
Further information about HDClarity, including the current protocol, is available at www.hdclarity.net, and the Central Coordination team is always happy to answer any questions (hdclarity-cc@enroll-hd.org). For regular updates, please see [@hdclaritystudy.bsky.social](https://twitter.com/hdclaritystudy).

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EHDN Platform Meeting: Deep Brain Stimulation against Chorea in HD

On 31 March 2025, EHDN hosted a [platform meeting](#) chaired by Anne Rosser (Cardiff University) to discuss the results of the

[HD-DBS study](#). Deep brain stimulation (DBS) involves the surgical implantation of a device that sends electrical signals to brain areas responsible for body movement. It is a well-established treatment for movement disorders such as Parkinson's disease – but might it also work in HD? Jan Vesper (Heinrich-Heine-University) presented his recent findings, which suggest that although stimulation of the globus pallidus (a subcortical brain structure)



is safe and well-tolerated in HD, further work is needed to confirm whether it can deliver clinically meaningful benefits.

Jan's presentation was followed by a lively discussion by a panel of experts, including Joaquim Ferreira (University of Lisbon), William Gray (Cardiff

University), Håkan Widner (Skåne University Hospital), and Jessica Köhli (Neurozentrum Siloah). More than 100 participants attended the meeting, but if you missed it, it's available on the [EHDN YouTube channel](#) [here](#).

Update: Funding Opportunities

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

Fellowship Programme

The fellowship program is a six-week programme organised by EHDN together with the International Parkinson's and Movement Disorder Society, allowing healthcare professionals from all over the world to attend an established HD multidisciplinary clinic in Europe and learn about HD care.

Introduction of new fellows

Six outstanding fellows were selected from this year's applicants following the review and evaluation process. The fellows come from various countries around the world, including Colombia, Oman, Chad, Ireland, Mongolia, and Romania.



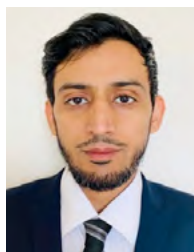
Matthew Stevens,
Ireland



Gulengar Carlos Othon,
Chad



Ana Dobri Nicoara,
Romania



Mahmood Khalifa,
Oman



**María Angélica Coronel
Mendoza,** Colombia



Namuun Erdenebat,
Mongolia



Fionnuala Margreiter



Juliana Bronzova

Organisation of host clinics

EHDN established contacts with HD clinics in the UK, Spain, and France, and is thankful to the host clinics for agreeing to host a fellow and organise a programme for them for a period of six weeks. Host clinics have now been organised for all fellows who are currently in contact with the clinics to discuss the placement and arranged dates. All placements are expected to take place before the end of 2025.

Pre-placement alumni meeting

In preparation for the placements of the new fellows, EHDN recently organised a pre-placement alumni online Zoom meeting with past and present fellows of the programme. Fellows from the 2024 programme shared their tips and practical advice with those just starting their placement this year, and this was well received. There was a chance to meet the fellowship team and pose any questions regarding the placement.

Planning for the 2026 programme

EHDN is currently collaborating with the International Parkinson's and Movement Disorder Society to finalise the 2026 fellowship programme, with the aim of launching the call for applications in the autumn.

Education

EHDN is currently working together with other organisations [e.g., International Parkinson's and Movement Disorder Society, European Reference Network on Rare Neurological Diseases, and the European Academy of Neurology (EAN)] to share information on HD courses and resources. A promotion agreement is currently being discussed with EAN, and similar initiatives are taking place with the other

collaborative partners. Several meetings were held during the recent EAN Annual Congress in Helsinki, where EHDN was an exhibition partner.

EHDN has organised an accredited online course in HD with the International Parkinson's and Movement Disorders Society, Pan American group (MDS-PAS) as a follow-up to the previous joint course. The course will be free of charge, held in the Spanish language, and will take place on two Friday afternoons (15 and 22 August 2025). The objective of the course is to enhance understanding of HD through a multidisciplinary approach, focusing on current challenges and

emerging perspectives. The Enroll-HD Regional Director for Latin America, the Iberian Peninsula, and Italy (Claudia Perandones) is the Course Director on behalf of EHDN. Several renowned international speakers have been invited to give lectures during the course. For further details and registration, [click here](#).

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, as well as some information on the grants and collaboration service.



Andreas Neueder, University Medical Center Hamburg-Eppendorf

Update: Lesley Jones Seed Funds

The EHDN has recently awarded seed funding to Andreas Neueder (University Medical Center Hamburg-Eppendorf) for an exciting new project titled 'DNA and RNA modification changes in direct lineage converted neurons of *HTT* mutation carriers'. HD is primarily a disease of the central nervous system, in which medium spiny neurons (MSNs) die first. Ideally, cellular models of MSNs should be of human origin, but these are difficult to access, and alternatives (such as those derived from induced

pluripotent stem cells) have some disadvantages. Andreas and his colleagues will employ a different approach to generate MSNs that will hopefully preserve the molecular age of the cells. The team will analyse changes in DNA and RNA to obtain insights into the age of the cells and also potentially into new disease mechanisms.



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) or Kinga Kolodziej (kinga.kolodziej@ehdn.org) for further information.

Update: Staff News



Naomi Ueda (Germany)



Anmol Guraya (UK)



Helen Finnegan Ford (Spain)

We are thrilled to welcome new Lancos Naomi Ueda (Germany), Anmol Guraya (UK), and Helen Finnegan Ford (Spain) to the EHDN team!

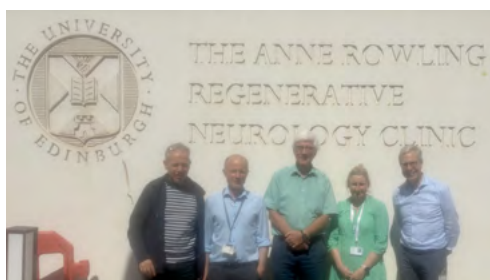
A full list of EHDN staff can be found at ehdn.org/about-ehdn/ehdn-structure/. For our latest career opportunities, please see: ehdn.org/about-ehdn/careers/.



EU Monitoring and EHDN Language Area Coordination Meeting

Catherine Deepprose

The most recent EU Monitoring and EHDN Language Area Coordination Meeting took place in Edinburgh, Scotland, 7–8 May 2025. This face-to-face meeting provided the opportunity to share the latest updates on Enroll-HD, clinical trials, working groups, and new initiatives. Particular highlights included presentations on the operational transition to Enroll-HD 2.0 and a fascinating scientific presentation from Flav Giorgini on somatic instability of the CAG repeat.



Postcard from Palm Springs 2025

Published by [CHDI](https://chdi.org/), 'Postcards' is a series of short videos aimed at non-scientists that convey the major themes, scientific breakthroughs, and clinical trial updates from each year's Huntington's Disease Therapeutics Conference held (most usually) in Palm Springs, California. Beginning in 2006, this series of conferences provides a unique forum where researchers from academia meet with pharmaceutical and biotechnology colleagues to discuss their latest progress, share ideas, and spark new collaborations. Following the conference earlier this year, both the [Postcard from Palm Springs 2025](https://chdi.org/postcard-from-palm-springs-2025/) and [scientific presentations](https://chdi.org/scientific-presentations/) are now available online.





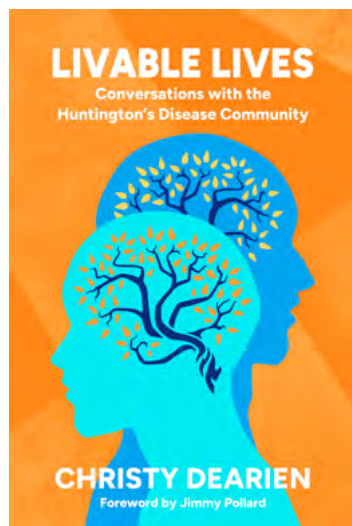
European Huntington Association

Ruth Blanco

Registration is officially open for the highly anticipated [EHA 2025 Conference in Romania](#)! The event will provide an unparalleled opportunity to connect, learn, and collaborate with leading experts, researchers, and patients in the field of Huntington's disease. This essential event will take place from September 25 to 28, 2025, featuring scientific presentations, engaging discussions, and valuable networking experiences.

The [Huntington Academy](#) is now LIVE and accessible to everyone! This innovative online platform offers a wealth of educational resources and expert-led modules on HD.

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Livable Lives by Christy Dearien

Published in late 2024, 50% of the proceeds from Livable Lives will go to HDYO. Author Christy Dearien explains, 'Livable Lives is the book I wish I had when my family first learned about HD. I wanted something I could give to people around me to help them

understand the many complicated issues HD families face. My hope is that readers will resonate with the stories in Livable Lives and know that they're not alone, and I hope the book will serve as a starting point for conversations with loved ones and care providers about the unique challenges of HD. We all have a story to tell and important lessons to share.'

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From left to right: Erich Wanker (Berlin), Lynn Raymond (Vancouver), Jennifer Oraha (Lund), Galen Wright (Manitoba), Åsa Petersén (Lund), Glen Sequiera (Vancouver), Niels Henning Skotte (Copenhagen), Huu Phuc Nguyen (Bochum)



Gordon Research Conference

The 2025 Gordon Research Conference (GRC) on CAG Triplet Repeat Disorders took place outside Lucca, Italy 25–30 May. 'Commonalities and Differences to Decipher the Pathogenic Mechanisms and Develop Effective Therapies' delivered cutting-edge talks on the clinical, pathological and biological aspects of inherited neurological disorders, including HD and fostered discussion among scientists across all career stages. The conference was supported by EDHN's Deputy Chair Åsa Petersén, who shares, 'It was a pleasure to take on the role of Vice Chair for this GRC together with X William Yang of UCLA and Chair Frederic Saudou of University Grenoble Alpes.' Åsa and William are now Chairs of the next GRC, which takes place in two years and will be supported by the newly elected Vice Chairs Elena Cattaneo (University of Milan) and Albert La Spada (UC Irvine).

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iMG Newsletter

Stop Press! Imaging Working Group

The third edition of the Imaging Working Group's newsletter will be published shortly. You will find this (along with past editions) on their webpage: ehdn.org/imaging-wg.

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Huntington's Disease Youth Organization

Jenna Heilman

In March, the [Huntington's Disease Youth Organization](#) (HDYO) hosted its second in-person [International Young Adult Congress](#) in Prague. The programme included new approaches to research education and topics such as a newly developed research terminology glossary and the Observational Study Dating Game. Charles Sabine discussed the Hidden No More initiative paired with a panel of professionals and community members addressing stigmas, and Jimmy Pollard ended the event

with a new keynote titled, 'Empowerment Through Gratitude'. It was truly inspirational!

As presented at the conference, HDYO has developed a [catalogue of terms](#) relevant to current clinical trials and research initiatives in HD. This terminology can be translated using the HDYO translation software and will continually be updated.

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HDYO

HDYO Survey Series



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Interview with Daniel Claassen, Chief Executive Officer at the Huntington Study Group

Professor of Neurology and Division Chief of Behavioral and Cognitive Neurology at Vanderbilt University Medical Center, [Daniel Claassen](#), is an internationally recognised clinical researcher in HD. In 2012, he founded the renowned Huntington's Disease Society of America Level 1 Center of Excellence at [Vanderbilt](#). In September 2024, he took up the position of Chief Executive Officer at the [Huntington Study Group](#) (HSG). We were excited to find out more about this exciting development for the HD community and ask Daniel about his mission and aspirations for HSG and HD care.



Daniel Claassen, newly appointed Chief Executive Officer at the Huntington Study Group

What motivated you to establish the Center of Excellence at Vanderbilt University Medical Center?

I came to Vanderbilt in 2011, having completed my medical residency and fellowship training, as well as gaining academic experience and a dedication to working in HD at the University of Virginia. I had come to see that HD is a very dynamic disease encompassing motor, cognitive, psychiatric, and social issues. I was also fascinated by the concept that HD is treatable from the standpoint of symptoms.

I was approached by several people, one of whom was the father of a person with HD and also a clinician at Vanderbilt who said that we really need to have an HD programme here – would you lead it? I said I'd love to. We started small, with between 50 and 100 patients attending the neurology clinic. We then added nursing, psychology, and social work provision, and now provide a fully multidisciplinary service. Over the years, the clinic has continued to expand, and we now have over 500 families.

One of the significant drivers of momentum in the clinic was the presence of clinical trials and the opportunities for people with HD to participate in clinical research. I realised early on that it's very important for people with HD to have the opportunity to participate in research – not only for themselves but also for their children and the broader community.

How did you get involved with the HSG?

One of my first experiences with HSG was through a trial conducted at Vanderbilt on deutetrabenazine (Austedo), and I also started to attend HSG annual meetings. We conducted several additional trials with the HSG and led some of the imaging analysis efforts for various trials. I was given the opportunity to serve as a co-principal investigator on the KINECT-HD trial by Neurocrine Biosciences, which further solidified my alignment with HSG.

One of the things that is really important about the HSG is the people who are part of it. It's a very close-knit community of like-minded folks who work with people impacted by HD. It was quite a surprise when the opportunity to become further involved in HSG came up! I received phone calls from a couple of people, including Andy Feigin, one of the former Chief Medical Officers, who informed me about potential leadership opportunities. It seemed a great opportunity, and a timely one, given that I had really enjoyed setting up and developing the clinic at Vanderbilt, and I was already thinking about how I could use this experience to help others grow their own clinics. It is fundamentally important for me to improve access to clinics for people with HD as well as to increase community engagement.

What activities have you been working on so far?

There are four main areas in which we are making progress at HSG. The first is education, and in particular,

‘I realised early on that it's very important for people with HD to have the opportunity to participate in research – not only for themselves but also for their children and the broader community.’

Daniel Claassen

ensuring that we nurture the development of our future generations of HD researchers and clinicians. We have some great people dedicated to initiatives like [ENGAGE-HD](#), which gets neurology trainees involved in HD care through a range of learning options. The second focus is on the

clinical aspects of HD. How do we treat, say, juvenile HD or deal with antipsychotic use? We want to develop consensus on key questions to better inform and support clinical practice. The third focus is on scientific advice. In the United States, we are often called upon to sit on scientific advisory committees, for example, and I believe we can leverage the expertise of HSG scientists to provide this more rigorously. Finally, we are examining site development, particularly ways of preparing upcoming clinicians and researchers for the administrative and business challenges that aren't taught in medical school.

We've developed a new governance model that will facilitate the progression of these four key topics through advisory councils. The chair of each advisory council will also be involved in a newly established executive committee. We have just announced the results of an election for the chair of the executive committee, which featured three incredible candidates: Danny Bega, Katherine McDonnell, and Erin Furr-Stimming. Erin will be taking up the position and I look forward to working with her. We're seeing great engagement, which is encouraging because it shows that people care, want to be involved, and support the democratic governance structure of HSG.

What critical challenges facing HD care will HSG address?

There are numerous challenges, but one that I think we really need to address is developing a care model for HD that focuses not only on symptomatic individuals but also on aspects such as brain health. In Alzheimer's disease, for example, people often ask, 'What can I do to keep my brain healthy?' and they visit brain health clinics to discuss topics such as cholesterol and exercise. Unfortunately, our clinics aren't currently set up for that, and the interdisciplinary care model in HD implies that there are obvious clinical symptoms that require treatment. One of the big challenges for HSG is helping clinics reposition themselves to support people who are at-risk or gene-positive much earlier. If we do that, we can let these people know about trials sooner, meaning that we will get much-needed answers more quickly.



The Claassen Lab at Vanderbilt University Medical Center

What are the synergies between HSG and EHDN?

One of the joys I experience as a physician working in HD is meeting people from diverse locations and backgrounds. I have always enjoyed attending the EHDN plenary meetings, and in my new role at HSG, I was eager to speak with Patrick Weydt and Jamie Levey about their strategies at EHDN. It's been really helpful because EHDN does a lot of things really well and has an excellent support system.

We're now focusing on how working groups between the two organisations can share ideas. We believe this is a really good first step because we

share many of the same challenges on both sides of the Atlantic. Patrick and I are keen to develop unified initiatives, progress towards finding better treatments, and address some of the complex issues in HD research and care.

What would be your advice for early-career clinicians and researchers who want to help improve the lives of those impacted by HD?

I believe the most important aspects are collaboration and effective communication with colleagues. Every site, clinic, and administrator is different, but when you get to talk about how people are doing things, you get to learn about what's working and what's not working, and incorporate it into your own vision. I've never met an HD clinician who isn't willing to collaborate or be engaged in mentoring. The HD field is unique while presenting numerous opportunities for collaboration with others, both in research and clinical care. Taking up opportunities offered by organisations such as HSG and EHDN is also a valuable step forward in this direction.

'The HD field is unique while presenting numerous opportunities for collaboration with others, both in research and clinical care.'

Daniel Claassen

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Dates for Your Diary

- **15 and 22 August 2025: Multidisciplinary Management of Huntington's Disease (MDS-PAS & EHDN Online Course)** in Spanish. Registration and attendance are free of charge. For further details and registration, click [here](#).
- **25–28 September 2025: European Huntington Association 5th Biannual Conference** takes place in Bucharest, Romania. 'Shaping our Future Together, We are the Change!' is aimed at health professionals and families. The registration deadline is 15 September 2025.
- **11–13 October 2025: Huntington's Disease Clinical Research Congress** takes place in Nashville, TN, USA. Early registration closes 1 August 2025 and regular registration closes 22 September 2025.
- **17 October 2025: EHDN Working Group Virtual Forum.** This is an internal event which will offer an opportunity for the Working Group leads to present to EHDN leadership, Think Tank, and each other. More details to follow!
- **26–28 October 2025: ERN-RND Annual Meeting 2025** will take place close to Munich, Germany.
- **1 November 2025:** Closing date for applications to the **EHDN Lesley Jones Seed Fund**. Find out more at ehdn.org/hd-clinicians-researchers/seed-funds/
- **15–19 November 2025: SfN Neuroscience 2025** takes place in San Diego, USA.
- **22–24 October 2026: EHDN & Enroll-HD 2026** takes place in Krakow, Poland. Watch this space for further details!

Would you like to share an upcoming event with our readers?
Please email the details to newsletter@ehdn.org

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