



Credit: Rex Features

World Mental Health day was held on 10 October. The day was first marked in 1992 as part of an initiative of the World Federation for Mental Health.

A special issue dedicated to the psychiatric symptoms of HD

Laura Spinney

This issue of the newsletter is dedicated to what is, for many families, the most disturbing and the least discussed aspect of HD: the psychiatric symptoms. Patryk from Poland and Bogdan from Romania introduce this difficult subject by describing their experiences of those symptoms, as gene carriers. We're particularly delighted to be able to include their words because they are speaking from parts of Europe that are under-represented in the collective voice of the HD community – a subject that Alzbeta Mühlbäck, who fields questions for the European Huntington Association's "Ask the Doctor" service, touches on in her interview on page 10. Following Patryk and Bogdan, Erik van Duijn and Jenny de Souza discuss the challenge of defining psychiatric phenotypes in HD, Olivia Handley and Michael Orth talk about capturing those phenotypes in later stages of the disease, and Peter Holmans and Lesley Jones address the subject of genetic modifiers of psychiatric symptoms in HD. We haven't forgotten our regular features, of course, so the remainder of the issue is filled with updates on Enroll-HD, clinical trials and funding opportunities, plus some tips on how to apply to EHDN's seed fund scheme, an invitation to take part in a survey and another to send us your photos. There is a permanent invitation to get in touch with us if you have something to say that you think EHDN's membership should hear. In that case, we're all ears!

**TAKE PART IN A SURVEY!
MAKE YOUR VOICE HEARD
ON THE QUESTION OF HD
AND RELATIVES' RIGHT
(OR NOT) TO KNOW.
SEE PAGE 6**

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–Please consult a doctor for medical advice–

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Living with the psychiatric symptoms of HD

Patryk

I was born 25 years ago in a small town in Poland. When I was four years old my maternal grandfather died after years of struggling with HD. I don't remember him well. I didn't understand what was going on.

When I was 21 my mother's sister got tested. The result was negative. This meant a lot to her as she was considering having children. She tried to convince the rest of us to get tested, but I was the only one who agreed – and she was the only one who knew about my decision.

At the hospital, a doctor asked me if I was sure I wanted to know the result. I said that I was. My thinking was that, if the result was positive, I would only have 20 years of full life left, so I wanted to know in order to get the most out of them. The doctor said that was very mature. A month later I got the result. It was positive. The doctor said that there were ways of managing the disease; I still had a lot of time, and medicine was always advancing. There was one other thing: my result meant that my mother also had HD, but she didn't want to know. I kept it secret from her for almost a year.

The result came at a bad time in my life – not that there's ever a good time. It was November, which always upsets me. I'd just moved to a new city and a new university, and I was struggling financially. I had also just moved in with my boyfriend, which should have made me happy, but my mind was slipping faster and faster toward winter. I was like a zombie or someone on autopilot. I lost my energy, my libido, and finally I lost my boyfriend, because I blamed my unhappiness on him. Just before he left, he advised me to see a therapist, which I did. My therapist was the first person to mention depression and to connect it to the test result. It was so obvious, why hadn't I realised? Every session with her I understood a little more, but it was too late to save my relationship.

A few months later I moved to Germany and the depression hit me again. I contacted a therapist locally and she gave me pills for depression, but I found some of the things she said odd. She asked if I thought HD was a punishment for being gay. She also advised me to forget my mother, who wasn't there anymore. Well let me tell you, my mum is still very much alive!

If I could give any advice to the medical community, it would be to learn a little more about those of us who come from HD families. And if I could give any advice to people in my situation, it would be this: if there is a person in your family like my mother, spend time with them, don't be afraid to talk about HD. If you have tested positive, don't overthink it. Do what makes you happy, realise your dreams, live every day like there will be no tomorrow. After all there may not be, even if you don't have HD.



Bogdan

My father and grandmother had HD. They didn't know anything about the disease, or how it can affect a family. They have both passed away and since I am an only child, it's just me now.



I tested positive for HD in 2017 and I already have symptoms; my balance, my speech and my mind are affected. I no longer work, but my wife, whom I love very much, supports me in every way. She was the one who spoke to me about my irritability and depression, and together we decided to do something about these symptoms, so we went to see a psychiatrist.

I don't want my family to suffer more by having to deal with my anger. They deserve better. It is not easy to talk

about psychiatric problems, but having the support of a doctor and a psychologist has made a big difference to us. My greatest hope and wish for everybody affected by HD is that a cure will be found soon.

Bogdan's words were kindly translated by psychologists Ramona Moldovan and Oana Cobeanu from Cluj-Napoca in Romania

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Defining psychiatric phenotypes in HD

Erik van Duijn and Jenny de Souza



Photo: Erik van Duijn



Photo: Jenny de Souza

The majority of HD patients show behavioural changes or psychiatric problems, with symptoms varying from shortness of temper to severe paranoid psychosis. These psychiatric symptoms are frequently reported to be the aspect of HD that both patients and their families find most distressing and hardest to cope with.

Behavioural changes and psychiatric problems contribute to a decline in everyday functioning, through their impact on work performance and social function, and may have a strong negative impact on quality of life. If managing problematic behaviours at home becomes too difficult for families and carers, a patient may be placed in a nursing home. For these reasons, it is important that behavioural symptoms are recognised and managed, and that they are also addressed in HD research.

Studies have shown that depression and irritability are more often reported in the early stages of the disease – even before the onset of motor symptoms – while apathy and psychosis are more likely to be reported in the later stages. There is, however, large variability in the manifestation of such symptoms in HD patients, and

as with other brain disorders, the psychiatric phenotypes are not always captured by the categories of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. Depression, for example, can present differently in HD, depending on whether it is associated with neurocognitive impairments or HD-related sleep disturbances. Also, typical neuropsychiatric manifestations of brain disorders, such as irritability, perseveration and apathy, are highly prevalent in HD, but they are not classified as psychiatric disorders.

Consensus is lacking with respect to the operationalisation and assessment of psychiatric phenotypes in HD. However, the instrument that is most often used to assess behavioural changes, and that has been found to be reliable, is the short version of the problem behaviours assessment (PBA-s) for HD, which was developed by the EHDN's behavioural phenotype working group. Using the PBA-s in large, longitudinal studies such as Enroll-HD allows us to see how these symptoms evolve over the course of the disease.

Since there is no established relationship between psychiatric phenotype – or the onset of psychiatric

symptoms in HD – and CAG repeat length, and specific psychiatric phenotypes do not seem to be hereditary, the origin of these symptoms is multifactorial. It is nevertheless likely that some psychiatric phenotypes – in particular irritability, perseveration and apathy – are closely related to changes in frontal corticostriatal circuits. They may be the result of degeneration in the anterior cingulate cortex and the orbitofrontal cortex, which is why they are referred to as “frontal behaviours”.

The follow-up of psychiatric phenotypes is complicated because the occurrence of behavioural changes and psychiatric symptoms is related, not only to progressive

neurodegeneration, but also to other psychological difficulties and neurocognitive impairments. Certain psychiatric phenotypes can be associated with executive dysfunction, which is why we recommend the inclusion of measures of executive function in future studies of psychiatric phenotypes in HD.

Erik van Duijn is at the Huntington Centre Topaz Overduin and the Leiden University Medical Centre, both in the Netherlands. Jenny de Souza is at the Birmingham and Solihull Mental Health Foundation Trust in the UK. They co-chair the EHDN’s behavioural phenotype working group.



Photos: G. Stautner, Artifax



Capturing phenotypic information in the later stages of HD

Olivia Handley, Enroll-HD Global Platform Manager, and Michael Orth, EHDN Central Coordination

As participants in Enroll-HD progress through the stages of HD, the numbers of participants in the middle or later stages of the disease inevitably increase. Two new instruments have been devised that take account of this evolution of the cohort, and preparations are now underway to evaluate them at several English-speaking study sites.

As HD progresses, patients’ mobility and cognitive abilities decline. They may feel less motivated to complete daily activities relating to personal hygiene and eating, and if they also become withdrawn, they may be less able to perceive the social and emotional implications of these changes in their behaviour. Our goal is to enable later-stage participants in Enroll-HD (stages III-V) to continue to participate, by reducing the assessment battery in such a way that the burden it imposes on participants, carers and study site staff is balanced by its capacity to answer important scientific questions. Those questions include: (1) how relevant is the expression of the HD mutation after disease onset (this information may influence future decisions to treat, for example with huntingtin-lowering drugs)?; (2) what modifies pathogenesis after onset, independently of age and CAG repeat length (this could influence the development of additional treatments)?; (3) what influences when a given endpoint before death is reached, such as the point at which 24-hour care is required?

To answer these questions two new instruments have been developed: the Unified Huntington’s Disease Rating Scale Structured Interview of Function (UHDRS SIF), which assesses functional ability, and the HD Clinical Status Questionnaire (HDCSQ). The HDCSQ captures information on critical milestones and events in the mid-to-later stages of HD, including information about living environment, hospital admissions, ambulatory status, falls, assistive devices, and the impact of behavioural and cognitive changes on daily living. Other important clinical endpoints relate to eating, swallowing,

sleep pattern reversal, incontinence, and speech and communication.

The two instruments will now be assessed for their ease of use and the quality of the data they capture, as well as whether they can be administered remotely – for example, by phone and through the intermediary of a participant's companion – or only face-to-face. Once they have been evaluated, the hope is that they will be incorporated into a large-scale, global observational study of later-stage HD – Enroll-HD Lite – and/or other HD clinical studies, and that they will also be useful in

the planning of clinical trials. For example, a robust database of clinical information on mid- to late-stage participants could serve as a basis for future studies aimed at developing tools and biomarkers for progression and prognosis (using biosamples and data collected in Enroll-HD). An example might be the association of late-stage clinical endpoints with maps of single nucleotide polymorphisms – as established by genome-wide association studies – that are likely to remain stable throughout a person's life. The end result, it is hoped, will be a win-win situation for participants and researchers.

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Genetic modifiers of psychiatric symptoms in HD

Peter Holmans and Lesley Jones



Photos: G. Stautner, Artifox

HD is a single gene disorder, susceptibility to which is determined by the presence of an expanded CAG repeat in the *HTT* gene on chromosome 4. However, there is considerable variation in the phenotypes shown by HD patients, which raises the possibility that other genes may influence the way the disease presents. Indeed, recent genome-wide association studies have identified genes associated with variation in [age at motor onset](#) and [disease progression](#), in addition to identifying DNA repair as a plausible biological mechanism in HD.

It is well known that HD patients have an increased risk of psychiatric symptoms such as psychosis, depression, irritability and apathy, compared with the general population, and that they also show progressive cognitive impairment. However, the causes of these symptoms are not well understood. A recent [study](#) involving our group investigated the genetic overlap between psychiatric symptoms and cognitive impairment

in HD and psychiatric disorders (schizophrenia, bipolar disorder, major depression, autism, obsessive-compulsive disorder and attention deficit hyperactivity disorder), neurodegenerative disorders (Alzheimer's and Parkinson's diseases) and general intelligence. The disorders in question have many genetic risk factors. We tested whether those factors influenced the risk of psychiatric and cognitive symptoms in HD using a sample of over 5,000 HD patients from the Registry and Enroll-HD databases. We focused on seven symptoms in particular: psychosis, depression, irritability, apathy, violent or aggressive behaviour, perseverative or obsessive behaviour and cognitive impairment. These were taken from the clinical characteristics questionnaire and defined as binary measures ("have you ever had X").

The study showed that increased genetic risk for psychiatric disorders tends to be associated with increased risk of psychiatric symptoms in HD. In particular, genetic risk for schizophrenia increases

the likelihood of psychosis and irritability, and genetic risk for major depression increases the likelihood of depression. Genetic risk for decreased intelligence is associated with cognitive impairment in HD. Interestingly, apathy is associated with genetic risk for decreased intelligence but not with psychiatric disorders, unlike depression. This suggests that apathy has a different aetiology from the other psychiatric symptoms of HD, which is consistent with previous findings that [apathy is the only psychiatric symptom to correlate with disease progression](#). Notably, genetic risk for other neurodegenerative disorders did not correlate with psychiatric symptoms in HD, indicating different causes. This finding reinforces those of the [Brainstorm](#) study, which found that psychiatric disorders show considerable genetic overlap, while neurological disorders are genetically distinct from one another and from the psychiatric disorders.

Taken together, these results suggest that the psychiatric and cognitive symptoms of HD have a common genetic aetiology with similar traits in the general population. They therefore provide a rationale for treatments applied in the wider population, for depression and psychotic symptoms, to be used for corresponding symptoms in HD.

The next steps will be to find the individual genes, gene variants and biological pathways that modify symptom presentation, using information from genetic studies of psychiatric disorders. It will also be important to refine the definition of symptoms by incorporating measures of severity and longitudinal progression. Eventually, it may become possible to derive genetic predictors of symptom risk of sufficient accuracy to be useful in the clinic, as is already the case with [Alzheimer's disease](#). However, this will likely require much larger cohorts of HD patients.

Peter Holmans and Lesley Jones are at the MRC Centre for Neuropsychiatric Genetics and Genomics, Cardiff University. They are members of the EHDN behavioural phenotype and genetic modifiers working groups. Lesley is also on the EHDN's Executive Committee and HD Science Think Tank.

IN BRIEF

Right to know: a survey

What do you think about the obligations doctors have to tell relatives about HD? Social scientists from the Society and Ethics Research Group at the Wellcome Genome Campus in Cambridge, UK, are conducting an online survey to gather the attitudes of people who live with HD, and their relatives. The researchers will compare these attitudes to those of people who have no experience of HD. This study has been designed to coincide with a legal case due to go through the UK courts in November 2019, that will explore whether doctors should have a legal duty to inform relatives about their risk of developing HD. The survey can be found [here](#). More information about the study and the case can be found [here](#).



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 Leonor Correia Guedes: leonor@euro-hd.net



Photos: G. Stautner, Artifax



Update: Clinical trials

Jenny Townhill and Tim McLean, Central Coordination

The following trials have been endorsed by EHDN. EHDN endorsement of a study protocol follows review by the EHDN Scientific and Bioethics Advisory Committee, which makes its recommendations to the Executive Committee. A formal letter of endorsement may then be issued to the study sponsor, signalling to the HD community that the study protocol has been reviewed and endorsed by a group of expert HD scientists and clinicians.



GENERATION HD1: Recruitment to this Roche global phase 3 trial of the huntingtin-lowering antisense oligonucleotide (ASO) RG6042 was restarted

over the summer of 2019, following a screening pause to allow for approval of an amendment to the design. The trial will enroll 660 participants with early manifest HD, with study participation lasting two years. The vast majority of participating sites have been activated and are now recruiting. A list of the 101 sites and their current status can be found [here](#).



PRECISION HD1 AND HD2: Recruitment to these two phase 1b/2a trials of allele-specific stereopure oligonucleotides, sponsored by WAVE Life

Sciences, is continuing at sites in Canada, Poland and the UK. Several new sites have been activated, or will be activated soon, in Australia, Denmark and the UK, with additional European countries in the process of start-up. PRECISION-HD2 is fully recruited and dosing in the fourth cohort is underway, with the first topline data for the trial expected by the end of 2019. Data from the four multi-dose cohorts of PRECISION-HD1 are expected in early 2020. Open-label extension studies for both trials will start soon and patients who have completed them will be invited to participate.



HD-DBS: Recruitment to this multicentre trial of pallidal deep brain stimulation for HD has been challenging due to the specific characteristics of the target

population: participants must have significant chorea that does not respond well to pharmacotherapy, but no significant cognitive impairment. Nevertheless, approximately 80% of participants have now been recruited, at sites in Austria, France, Germany and Switzerland, with recruitment due to be completed early in 2020. For further information, please contact: dbs@euro-hd.net



PACE-HD: Recruitment to this activity intervention study, sponsored by Cardiff University,

was completed in May 2019. Follow-up visits continue at the seven participating sites in Germany, Spain and the US, with results expected in the first half of 2020.

Send us your photos!

Whether you're affected by HD personally, or you're a carer, clinician or scientist working in the field, we'd like to publish your photos in the newsletter. If you have an image that provides an insight into your daily life, that you think might interest, inspire or entertain other EHDN members, please send it to us – along with a few words explaining who you are and what the image shows. If the idea catches on, we might even turn it into a regular feature. For now, it's an experiment.

Mike's pens



EHDN's Michael Orth has kicked the ball off with this glimpse of his life as a clinician-researcher. The Generation-HD trial in which he is taking part requires participants to undergo lumbar punctures. A pre-packaged, sterilised pen is used to make a single mark on the needle involved in that procedure, after which the pen has no more use in the study. Rather than throw his pens away, Michael has collected them and put them on display. "Each pen represents a successful lumbar puncture!" he explains.

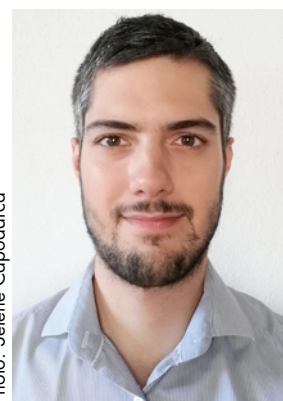
Photo: Michael Orth



Olivia Handley



Selene Capodarca



Luís Garcez

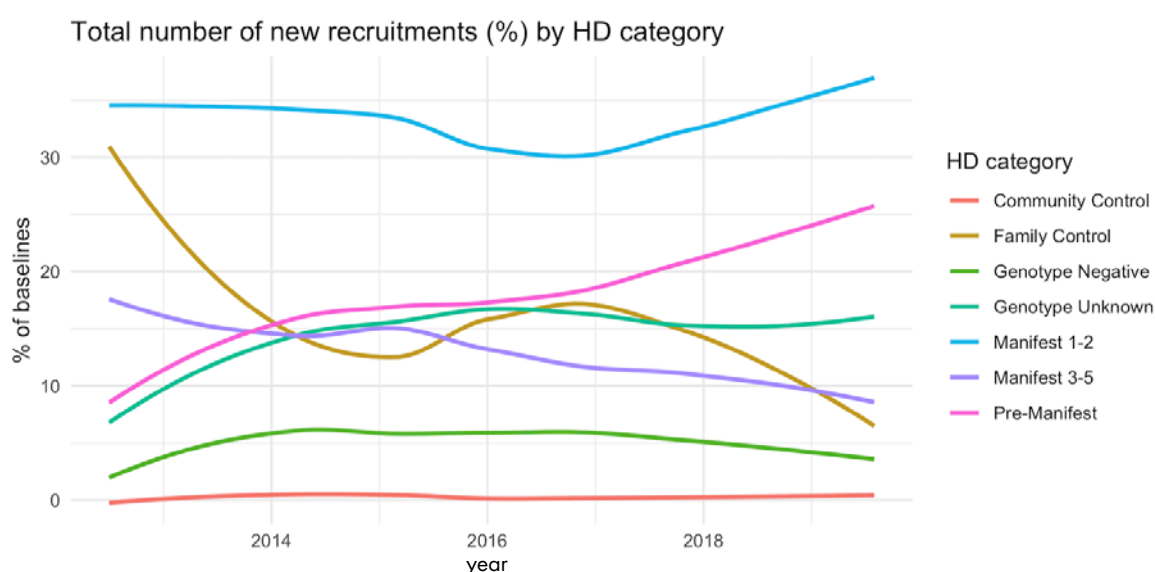
Update: Enroll-HD

Olivia Handley, Selene Capodarca and Luís Garcez

In 2017, global recruitment to Enroll-HD was projected to reach 20,000 participants by 2019 (it had reached 22,401 by 30 September 2019). A statistical model was developed to estimate the size of the Enroll-HD cohort over time and to guide optimisation of its composition – both in terms of participants and sites. It became clear that the composition was not evolving in a way that conformed to the study objectives, particularly in light of the demand for participants in clinical trials, and at the end of 2017, the Enroll-HD team communicated a new, two-part strategy to study sites:

- Prioritise recruitment of at-risk, premanifest and early-stage participants, since these will be in most demand for current and future clinical research
- Restrict recruitment in the mid-to-later stages of the disease, since study visits can be particularly burdensome for these participants, as well as for their carers and site staff, and the assessment battery includes several tasks that have reduced sensitivity in the advanced disease

The goal of the new strategy is not to increase the total number of participants, but to target recruitment towards those most needed for research. And it is working. As shown in the chart below, the percentage of participants in premanifest and early manifest stages increased in 2018 and continues to do so in 2019.



Olivia Handley is the Enroll-HD Global Platform Manager,
 Selene Capodarca is the Enroll-HD Global Project Manager,
 Luís Garcez is a statistician at the University of Lisbon's Faculty of Medicine

Photo: G. Stauner, Artifox



Funding and other news

Fionnuala Margreiter, Grant & Collaborations Manager

- The first call for new members to join 24 existing European Reference Networks (ERNs) was opened on 30 September and will remain open until 30 November 2019. EHDN centres that aren't already members are strongly encouraged to apply to join the [ERN on rare neurological diseases \(ERN-RND\)](#).



- Calls are open for individual grant applications to the [European Research Council](#) with various deadlines.



- The next round of applications for the EHDN/International Parkinson and Movement Disorder Society (MDS) six-week clinical fellowship programme will be advertised soon. Keep an eye on the [website](#) for more details.



Correction: In our last issue, published on 1 July 2019, we mislabelled a map showing the country origins of the 2018 EHDN/MDS fellows and their destinations under the fellowship programme. Fellow David Aguillon hails from Colombia, not Columbia. Our apologies.

Photo: Anne Nørremølle



EHDN's seed fund scheme: how to apply

Anne Nørremølle and EHDN's Scientific and Bioethics Advisory Committee

Under the EHDN's seed fund scheme, funds of up to €50,000 are granted to fast-track pilot studies required to apply for larger grants or to estimate the statistical power needed for larger studies. The scheme is particularly suited to new lines of research where very preliminary data are insufficient to validate a working hypothesis.

There are two calls for applications each year and the EHDN receives between 10 and 30 applications per call. These are reviewed by its Scientific and Bioethics Advisory Committee (SBAC), which provides recommendations to the Executive Committee (EC). The EC takes the final decision on which projects to support.

Detailed information about the scheme, and a fuller version of this article, can be found [here](#). In this newsletter we simply extract some key pieces of advice on how to write a successful application.

A seed fund project is a project that thinks "out of the box" and that therefore has the potential to move HD research in new directions. It does not have to lead to the full elucidation of a hypothesis, but it should be capable of generating results based on which more extensive funding can be obtained – and the application should spell out how the pilot data will be used in future research or grant applications.

The aim should be clear and achieving it should be feasible with the amount of funding requested. The applicant must demonstrate that they have access to necessary resources and expertise, especially if they are new to HD research. In clinical projects, for example, they should have access to a patient cohort and be able to describe exclusion and inclusion criteria. It is essential that they have considered ethical issues and obtained ethical approvals for the project where necessary.

The rationale and design of the project should be described, including the methods, the samples or patients to be analysed, and a power calculation as an estimation of the number of samples needed to produce significant results. The applicant should be able to demonstrate familiarity with the HD literature by including relevant references as background. Preliminary data may be included, for example to provide proof of concept or to demonstrate the applicability of novel methodologies.

The application should be written in an accessible way, following the guidelines built into the online template and including short appendices where appropriate. Finally, it should contain all relevant information as there will be no opportunity for the SBAC to request clarification.

Anne Nørremølle of the University of Copenhagen is a former chair of the SBAC. The next deadlines for application to the seed fund scheme are 1 March and 1 November 2020.

Spreading the word:

Interview with Alzbeta Mühlbäck

Born in the former Czechoslovakia in 1980, Alzbeta Mühlbäck trained as a neuropsychiatrist in what became the Czech Republic, but gained most of her experience of HD in Germany – first in Taufkirchen, now in Ulm. Here she explains how she came to be the doctor who fields questions for the European Huntington Association (EHA)'s online "[Ask the Doctor](#)" service, and what she has learned in that role.

What was your first encounter with HD?

I was a young student and twins came into the movement disorders clinic where I was working. They were in their 30s, a man and a woman, both gene carriers. My professor thought they would start showing symptoms in about five years' time. They were both so alive, meeting them was one of the reasons I decided to specialise in neurology and to focus on HD. I went for the obligatory one-year training in psychiatry, gravitated to psychotherapy, and never returned to neurology. I'm also qualified as a genetic counsellor in neuropsychiatric diseases.

How did your association with the EHA come about?

I met Astri [Arnesen, EHA President] at one of the annual CHDI therapeutics conferences in Palm Springs. She gave a very honest presentation about what it was like to belong to an HD family, and afterwards I congratulated her. I felt it was important for the scientists present to hear that. We had a conversation about what was needed, going forward. She had already floated the idea of an online "ask the doctor" service, but doctors had told her such a service wouldn't be possible without meeting the patient. I didn't see that as an obstacle, necessarily.

Why not?

You would need to see the patient if the question concerned therapy, but I felt that a lot of the questions that people might ask would not be about that. I thought they would be more along the lines of, what should I do when my partner who has HD becomes aggressive?



Photo kindly provided by Alzbeta Mühlbäck

What should I tell my children when they ask about HD? The sorts of questions I get every day in my clinic, in other words. So we launched the service on the EHA website, and it turned out I was right. When a question comes about medication, I refer the person to a doctor – I don't provide online therapy – but such questions are rare. It's not about that.

“When a question comes about medication, I refer the person to a doctor, but such questions are rare. It's not about that.”

Where do the questions come from?

All over! India, Australia, Latin America... not just Europe. The questions come in many languages. I call on the national patient associations to help me translate them, and in the process I'm establishing a network of global contacts – including clinicians specialising in HD – to whom I can refer people in different regions if need be. The people writing to me tend to value their privacy, perhaps because the disease is heavily stigmatised in their country. There aren't so many young people – they are very well looked after by the Huntington's Disease Youth Organization, which has a similar [service](#).

What kinds of questions do people ask?

By far the biggest category – around 70% – concern psychiatric and behavioural symptoms. Often these are the symptoms that come on first, and families do not understand why their relation is behaving strangely. Or perhaps a person who knows they are at risk is worried that a burnout at work is the first sign of the disease. I explain about the changes in personality that accompany HD, the fact that it causes people's reaction times to slow and impairs their ability to recognise faces. But I also explain that the causes of the behaviour they are concerned about could be something else in their life, besides HD.

Do you get questions about the genetic test?

Yes. In our field we recognise that, at the moment that people receive their test results, they may not be able to digest all the information that is being fed to them, and questions might occur to them later. Sometimes I receive those follow-up questions in my clinic, sometimes via the EHA website; sometimes from the patient themselves, sometimes from family members.

Do you see geographical variation in the questions?

There are some countries where HD patients just aren't "visible" at all. Local neurologists may say that such patients are very rare in their country, so we have to



Photo: Ask the doctor

ask, where are they? We know, statistically, that they must exist. In India, for example, people don't want others to know that they have HD in the family, so they hide their affected relatives. But this is also the case in parts of Europe. HD is far more visible in the Czech Republic than in Slovakia or many Balkan countries, for example, which may partly reflect the fact that the infrastructure for caring for patients is also much better developed in the Czech Republic than in those other countries.

Finally, is there anything you would like to say to EHDN members reading this?

I think that as clinicians and scientists we could all do better at sharing our expertise in HD across borders. We all work in a specific country, but we are all, also, European. We could do more to even out those inequalities in care and information that exist across the region.

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Dates for your diary

Save the dates for:

- [15th Annual HD Therapeutics Conference](#), Palm Springs, California, USA, 24-27 February 2020
- [Huntington's Disease Youth Organization's 1st International Young Adults Conference](#), Glasgow, UK, 9-11 May 2020
- [The 10th European Conference on Rare Diseases & Orphan Products](#), Stockholm, Sweden, 15-16 May 2020
- [EHDN2020 plenary meeting](#), Bologna, Italy, 10-12 September 2020 (details to come)



Photo: University of Strathclyde