



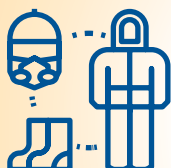
WEARING MASK



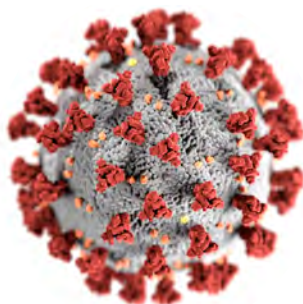
HAND WASHING



AVOID CROWD



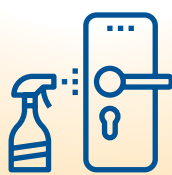
PROTECTIVE CLOTHING



TEMPERATURE CHECK



STAY HOME



CLEANING



DOCTOR ADVICE

**CALLING ALL HD RESEARCHERS: APPLY NOW FOR A SEED FUND. DEADLINE 1 NOVEMBER! SEE PAGE 12**

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

## A special pandemic issue

Laura Spinney

Pandemics, it is said, kill in three ways: the disease kills, the disruption to health systems kills, and the disruption to the economy kills. Covid-19 has shown that it conforms to the pattern, and it has certainly disrupted the lives of all those in the HD community since it emerged half a year ago. Reflecting that, this issue of the newsletter is dedicated to the impact it has had on all aspects of life for this community. We catalogue the problems it has created, of course – but not only. The articles that follow attest to the adaptability and endurance of our members, and to the positive trends that the pandemic has unleashed or accelerated. Foremost among these is telemedicine, which has stepped into the breach of lockdown and enabled care and research to continue in the absence of face-to-face contact. "Among the countries reporting service disruptions," the World Health Organization stated on 1 June, announcing the findings of a global [survey](#) of the status of prevention and treatment services for noncommunicable diseases, "58% of countries are now using telemedicine... to replace in-person consultations; in low-income countries this figure is 42%." In this edition, family members, carers, doctors and scientists report back from the Covid-19 frontline, and describe that brave new world.

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## Telemedicine comes of age

Alzbeta Mühlbäck, Ulm University, Germany

The current pandemic has forced us to contemplate comprehensive care approaches for vulnerable patient groups.

We know that the prevalence and mortality rate of Covid-19 varies substantially between groups and that comorbidities – especially chronic diseases – are an important risk factor. As clinicians we remain extremely concerned about the risk Covid-19 poses to HD patients, because knowledge about the course of infection in this population is limited.

In general, the rarer and more severe the pre-existing condition, the greater the uncertainty and anxiety expressed by patients, families and the organisations that represent them. However, HD families have shown excellent coping skills during this pandemic, and health professionals have shown great willingness to embrace telemedicine – with remote solutions being implemented in various European countries within a few days or overnight. A range of approaches has been adopted to connect clinicians with families, from mobile applications to Skype and Zoom. In countries where telemedicine support already existed, such as the Netherlands, adapting to the new situation has been easier.

The pandemic is a rapidly changing situation and information about the disease is also accumulating rapidly. Professional associations such as EHDN or the European Reference Network on rare neurological diseases (ERN-RND), and lay associations such as the European Huntington Association (EHA) and its national counterparts, play a critical role in the circumstances, by guiding the HD community towards information that is relevant to it. There is a pressing need to make that



Alzbeta Mühlbäck

information available without barriers, especially language barriers, and in a regionally appropriate way – through regional contact persons and by tailoring it to local health and social systems. There is also a need to support local healthcare professionals and connect them with the information, infrastructure and other professionals they may need in order to provide better care to their patients.

The longer term aim has to be to keep improving telemedicine for people with HD even outside pandemic conditions. This will involve developing and evaluating plans to ensure high-quality remote care, guiding users through the different telemedicine approaches and evaluating the performance of wearables that monitor health-related activity, such as Fitbit or the Apple watch.

Though we would have preferred never to have known Covid-19, it has provided us with a golden opportunity to develop high-quality telemedicine for the future and to establish the infrastructure that will improve care in under-served regions of Europe.

Neuropsychiatrist Alzbeta Mühlbäck fields questions for the EHA's ["Ask the Doctor"](#) service.





## Coping with lockdown – the family's view

Cristina Ferreira, Lisbon, Portugal

The last day I was physically with my mother was 26 February. That was before Covid-19 arrived in Portugal.

My mother is in an advanced stage of HD and unable to eat, speak or walk. All her basic needs are supplied by professional carers and nurses. She is incontinent, fed artificially, and receives a daily cocktail of symptomatic treatments. She is constantly monitored, and undergoes frequent tests and weekly medical surveillance. I don't think she would have survived this crisis outside the care home in which she lives.

My first concern, at the beginning of the crisis, was to isolate her as quickly and effectively as possible. Next I had to obtain her medication and other items necessary to ensure her comfort for the coming months. I had to anticipate her needs as far as possible, as I commute daily between Lisbon and my workplace further south, and it was possible that I myself could become infected and have to self-isolate at home.

All my mother's medical consultations were cancelled, but fortunately her neurologist had prescribed medication to last her between half-yearly consultations. It was necessary to collect tetrabenazine, which is vital for controlling her movements, and in Lisbon this was provided exclusively by the pharmacy of the Hospital de Santa Maria, which was already dealing with Covid-19 cases. Later a law would decentralise the distribution of such drugs, but for me there was simply no time to enquire about local solutions. Meanwhile, long queues were forming at local pharmacies, which quickly ran out of masks and hand sanitiser.

My mother was isolated in her room and deprived of visitors and complementary therapies. Though she is always in a

good mood, it saddens me that she is unable to ask, simply, what's going on? I feel it is important to explain to HD patients why Covid-19 has made visits less frequent, and to repeat those explanations often so that they don't feel abandoned and blue. Thankfully, my mother's home adopted video calling. She communicates clearly using the sparkle in her eyes, glaring when interested and blinking to say yes. Every day I am afraid that her light will go out, but there's no doubt that the ability to communicate visually has been critical to her during this period – providing a much needed channel to the outside world and compensating for her lack of visits.

Telemedicine, too, holds huge promise for patients like my mother, because it removes the need for physical displacement and can actually make consultations more efficient. At the Hospital de Santa Maria, for example – whose neurology outpatient department my mother usually attends – construction works have been scheduled for a decade. Space is short there, manoeuvring stretchers, wheelchairs and patients is difficult, and the hospital does not provide ambulance transportation for HD patients whose income is above a certain minimum (this criterion does not apply to patients with other rare, chronic diseases). Taking my mother to the hospital involves complicated logistics, high cost – around 100 euros a trip – and is physically tiring for her.

Perhaps Covid-19 will have a silver lining, then, improving quality of life for patients if such things as telemedicine and video calling become routine. We shall see. In the meantime, as Portugal slowly comes out of lockdown, I will soon be able to visit Mum once a week.



Cristina and her mother





## Coping with lockdown – the doctor's view

Hugh Rickards, National Centre for Mental Health, Birmingham, UK

Since the lockdown started in the UK, our clinical team has developed a more proactive approach to our 350 HD patients and their families. We've done this in order to keep as many of them as possible out of hospital, and this has meant organising video or phone consultations with the families, with the help of our local specialist HD advisor (supplied by the UK Huntington's Disease Association).

The majority of our patients are coping really well with the situation. Many are content to lead less busy lives and have set up undemanding routines. A number of families have commented that video consultation suits them (no need to dress up and get into the car, no need to find a parking space or wait in a waiting room), so this may lead to changes in our service in the future. Some patients and relatives do miss the routine of clinic, however, and it is a bit harder to pick up on relatives' concerns over a video link. Another thing we've learned is that there may be more people in the room than just the ones you can see by video, so it's always good to ask who's present!

We have come across a few "problem situations". First, some families are locked down with children or adolescents and this can lead to a heightening of tensions between demanding family members, which are usually managed by the patient's spouse. There's no one solution to this, but in general, working with all concerned so that everyone understands the nature of "HD brains" usually generates solutions.

Some of our patients can't understand or adhere to lockdown rules, which can be particularly difficult if there's another vulnerable person in the home. Again, there's no single solution to this problem, but it is possible to minimise risk, anticipate the needs of the person with HD, and attempt to set up novel home-based rituals.

A small number of people with HD worry about the risk posed to them by Covid-19, but in our experience this is

relatively rare. In general they worry less than people who are not affected by HD.

One of the more surprising problems we've encountered is the effect lockdown can have on spouses or other primary carers. A number of spouses are experiencing a more intense grief response than usual, perhaps because lockdown has imposed a closer interaction with their partner and required them to think more about end-of-life decisions while removing other distractions. There have been more conversations between spouses and our team members concerning grief for the person with HD, who is still alive but "not the same person".

Working as a clinical team when physically separated is challenging. We have a short team meeting each morning to bring ourselves up-to-date and boost morale. Most of our team say that we spend more time together now than when we were all in the same building... It looks like telemedicine is here to stay!

## EHDN plenary postponed

Patrick Weydt, Co-Chair, EHDN Executive Committee



The EHDN2020 plenary meeting was due to take place in Bologna, Italy, this coming September. This is no longer possible, as the EHDN recognises the enormous burden the pandemic has placed on the HD community globally and the region of Bologna particularly. The meeting has therefore been postponed by a year and will now take place from 10 to 12 September 2021, while a shortened virtual interim meeting will be held on the afternoon of Friday 11 September 2020. This "bridging" event will feature online sessions on two general topics: scientific advances since the EHDN2018 plenary meeting, and clinical trials.



## A medical opinion: Covid-19 and HD

José López-Sendón, Hospital Universitario Ramón y Cajal, Madrid, Spain

During the recent outbreak I was redeployed to the infectious diseases department of my hospital to assist Covid-19 patients. From my brief experience there I gained some insights into how the disease might affect HD patients.

Individuals with HD are not at higher risk of getting infected with Covid-19 per se. However, several circumstances associated with the disease might increase their risk, such as living in a nursing home, attending a daycare facility or lacking awareness of recommendations concerning social distancing, hygiene, masks and so on. Where these circumstances apply, special measures must be taken to minimise the individual's risk of infection.

The best documented risk factor for complications associated with Covid-19 infection – including among HD patients – is age. Patients experiencing dysphagia or who are at risk of aspirative pneumonia, such as advanced HD patients, could also be at higher risk of developing a severe form of Covid-19 if they become infected. However, it must always be borne in mind that any healthy individual of any age can become critically ill with Covid-19.

The rate of patients presenting with acute but not Covid-19-related conditions during the worst part of the outbreak was lower than expected. There may be a number of reasons for this, but doctors worldwide have underlined the importance of seeking medical advice for serious health problems – and that applies to HD patients too. If they experience a worsening of symptoms, they should contact their healthcare provider without delay. Some patients may indeed have noticed such a worsening, in the context of lockdown and associated disruptions to care schedules, but HD advocacy groups have issued recommendations and resources to help them manage these during the pandemic.

Finally, I would like to stress the importance of closely following official advice on how to protect oneself and others from Covid-19.



*José López-Sendón is a neurologist who specialises in movement disorders and is closely involved with Spain's national HD association, [ACHE](#).*



## 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 Kristina Bečanović:**  
[kristina.becanovic@euro-hd.net](mailto:kristina.becanovic@euro-hd.net)





## Covid-19 and lab research

Lesley Jones, Cardiff University, UK

Many research labs closed partially or completely during lockdown. Most managed to do so in an orderly fashion, protecting precious or irreplaceable resources, but some researchers have been diverted to Covid-19-related research and inevitably the disruption will have knock-on effects. What will be its impact on HD research?

We have all learnt to work from home. This has advantages, such as no commuting and fewer disturbances, and many researchers have used the enforced hiatus to analyse and write up data, read and plan experiments – all worthwhile activities. But there have been disadvantages too, including isolation and wellbeing issues, and difficulties in managing researchers on short-term contracts, as well as in negotiating research contracts in the context of uncertainty about the timing of a return to research. Working outside the lab has been less of a problem for those carrying out research *in silico*, but even they are likely to need more experimentally and clinically derived data in the long run.

Universities have many responsibilities and the need to protect students and staff has understandably come first, though research has usually been taken into account. Many university labs have been open for “essential” research only, but the definition of “essential” has varied

from institution to institution and researcher to researcher, and this has led to unseemly competition between some groups to be the first back in the lab!

Lab researchers have some advantages over other professions. They are used to working with personal protective equipment and risk assessments are a way of life for them. Even so, the need to observe social distancing rules has required them to accept new ways of working. Now that lockdown restrictions are being eased, most labs are opening up to small numbers of researchers first, with a view to identifying any problems that need to be solved ahead of the return of their colleagues.

Potential longer term effects are harder to predict. The economic fallout from the pandemic makes it almost certain that research funding will be more difficult to raise. Some not-for-profit organisations have been hit hard as they can no longer carry out their usual fundraising activities and supporters have less money to give. Cancer Research UK recently announced a big fall in funding, for example, and its experience has been repeated throughout the charity sector. Government funding for research may also drop as resources are diverted to other sectors of the economy. This will be determined by political decisions that may differ from country to country.

My personal feeling is that the pandemic will cause delays in ongoing research programmes, rather than their outright suspension, but that finding funding for new projects will be challenging. There will be less enthusiasm for novel, relatively high-risk research areas in particular. HD is nevertheless in a good position: there are experimental drugs in trials or coming into trials that address several different mechanisms of action, and there is recognition that finding a treatment for this previously intractable neurodegenerative disease might open the doors for novel treatments in other, similar disorders.

*Lesley Jones studies the genetics of HD in a lab. She is also a member of EHDN's Executive Committee and its HD Science Think Tank.*

## Update: Clinical trials

Jenny Townhill and Tim McLean, Central Coordination

Clinical trials have been significantly affected by the Covid-19 pandemic. Challenges include increased demands on healthcare services, restriction of visits to healthcare facilities and changes to staff availability. Some staff and trial participants may also have been required to self-isolate, making it more difficult for investigators to maintain medical oversight.

Regulatory authorities such as the US Food and Drug Administration and the European Medicines Agency rapidly published guidance on the management of clinical trials during the pandemic, which prioritised the health and safety of trial participants, trial integrity and compliance with good clinical practice. The fundamental premise of the guidance is that any measures should be proportionate and based on benefit-risk considerations. It emphasised the need for continued compliance with national and local regulations, an evaluation of the impact of travel restrictions and social distancing requirements on participants and staff, and the availability of trial staff to perform assessments, enter study data, send notifications for serious adverse events and, more generally, comply with the protocol. While there is some leniency in the timelines for reporting protocol amendments and deviations, it remains essential that all such instances are fully documented.

Where a trial participant has been unable to attend study visits, alternative solutions such as remote contact via telemedicine or home nursing – if possible with social distancing – have been implemented to ensure the identification of potential adverse events, the conduct of safety assessments, and continuous medical care and oversight. Limited opportunities for on-site monitoring have meant that alternative methods of monitoring data quality have been required too, and disruptions to supply chains have posed a particular challenge for some trial sponsors by threatening the reliability of provision of Investigational Medicinal Products.

Clearly the pandemic will have an adverse impact on participant recruitment and possibly retention in most clinical trials, and timelines will need to be reset for study start-up, recruitment and close-out. It remains to be seen if the integrity of study data will be affected.



Photo: G. Stauner, Artifax

All HD clinical trial sponsors have issued study-specific guidelines to their sites with the primary intention of protecting the safety and wellbeing of participants, while allowing the study to continue where national, local and institutional regulations and guidance permit. EHDN-endorsed [clinical trials](#) have continued to make progress during the pandemic, even achieving some notable milestones:

The Roche studies of tominersen (previously known as RG6042) continue, with recruitment into the Generation HD1 trial recently completed. WAVE Life Sciences' PRECISION HD1 and HD2 studies, and associated open-label extension studies, continue. The University of Düsseldorf's HD-DBS trial has temporarily paused recruitment for safety reasons, during the pandemic, but continues to support sites to maintain safety follow-up assessments of recruited participants. Triplet Therapeutics' SHIELD HD natural history study has started recruiting at a small number of sites, with the first participant screened in May. Additional sites will be added as local conditions and guidance allow.

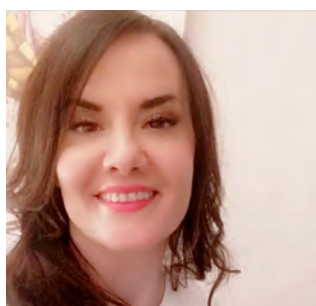
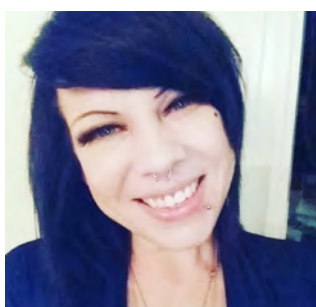
Patients and families involved in clinical trials during the pandemic are advised to follow recommendations provided by their clinical trial site teams, as sponsors continue to monitor the situation to ensure patient safety and data integrity.

Lockdown restrictions are gradually being eased, in some regions, but it is likely to be some time before clinical trials can resume previous levels of activity, with constraints and different working practices needing to remain in place for many more months. Some of the practices that have been introduced during this pandemic, including remote assessments, may become more permanent features of study protocols in future, if they prove to make trials more efficient and less burdensome to participants.







**Daisy Abreu****Selene Capodarca****Olivia Handley****Michael Orth****Jen Ware**

during this challenging period, CHDI has initiated an exceptional payment for phone contact visits [see box].

Approximately half of all sites anticipate re-opening for participant visits by 1 July, although for others this date extends up to 1 October, and many are currently unable to give a date for re-opening. Almost 80% of sites expect to resume at or above their usual capacity, while the remainder expect visit frequency to be reduced.

Enroll-HD is an observational study, and ongoing phase 3 clinical trials are considered a higher priority. However, Enroll-HD not only informs and supports those clinical trials, the data it gathers are of critical importance to HD research in general. Of equal importance are study visits which provide an opportunity to support HD families and carers in these exceptional times.

#### Phone contact

**Enroll-HD study sites** are advised to contact participants who have either had their follow-up visit cancelled or are due for a follow-up visit but cannot attend due to site closure or restrictions, or because they are reluctant to come into the clinic at this time. The following information should be given or obtained:

- Reiterate the value of the Enroll-HD study and ask if the participant is willing to continue in the study
- Create a phone contact visit and complete the missed visit form
- Update comorbidities and pharmacotherapy forms with any other new and relevant information, including whether the participant has had a Covid-19 infection

Note: video and phone visits cannot be considered for Enroll-HD as this option is not approved under the current protocol and informed consent form. In addition, Enroll-HD assessments have not been validated for use in a video/telemedicine environment.

*Daisy Abreu is a clinical statistician at the University of Lisbon;  
Selene Capodarca is Enroll-HD Global Project Manager for EHDN;  
Olivia Handley is Enroll-HD Global Platform Manager for EHDN;  
Michael Orth is EHDN's Science Director;  
and Jen Ware is CHDI's Director, Experimental Design*



*Astrid and Arvid on Astrid's 80<sup>th</sup> birthday, catching king crabs in the Arctic Circle*

Of her career as a politician, Arvid says, "She was a surprising success." She developed a reputation for engaging easily with people and in later years was looked up to as a role model, especially by younger women. Having left politics for the first time in 1987, she returned to it in her 70s, dedicating herself to the affairs of the elderly and serving in the Norwegian parliament until a year before her death.

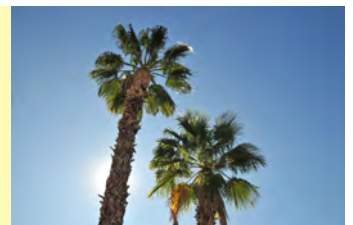
"Astrid was a warm, listening and wise person," says Astri Arnesen, President of the European Huntington Association, who recalls how Astrid helped her cope after her mother was diagnosed with HD. She also had a special energy and was highly committed to the causes she believed in. "I remember very well when she was appointed state secretary at the age of 77," Astri goes on. "I saw her biking to the office in a red leather jacket. Tough and full of life, she wanted to continue to contribute to policy-making. And she did."

## In memoriam: Astrid Heiberg

EHDN would like to pay tribute to Astrid Heiberg, who died peacefully at home this spring, aged 84. A distinguished psychiatrist who enjoyed a parallel career as a politician in her native Norway, Astrid always maintained links with the HD community through her husband, Arvid Heiberg. Arvid was active in EHDN from its early days, and he continues to care for HD patients and to chair the data safety monitoring committee for Enroll-HD.

Starting in the early 1980s, the Heibergs became convinced that the psychiatric aspects of HD were as if not more important than the motor component. Astrid brought her psychiatric knowledge to the question and became involved with HD families in Norway, often visiting nursing homes with her husband. She also attended many EHDN events and was well known to the network's members.

## Annual CHDI therapeutics conference



The scientific presentations from the 15<sup>th</sup> Annual HD Therapeutics Conference, held in Palm Springs, California from 24 to 27 February this year, are now [online](#). A "Postcard from Palm Springs" video, which can also be viewed [online](#), outlines some of the conference's major themes for HD families, including updates on therapeutic candidates in or approaching clinical trials.



## Fellowship exchange programme: from Romania to Manchester

Oana Cobeanu, Cluj-Napoca, Romania

Being in Manchester at the end of 2019, as a guest of the Manchester Centre for Genomic Medicine, was one of the most complex but satisfying professional and personal experiences I have ever had.

I had been granted a fellowship under the sponsorship of EHDN and the European section of the International Parkinson and Movement Disorder Society (MDS), and this gave me the fantastic opportunity to attend counselling, predictive testing and management clinics, as well as home visits, multidisciplinary team meetings and seminars on research and the ethics of genetic testing.

Many aspects of working with an HD family became clearer for me, as I became more self-sufficient. These include the step-by-step assessment and follow-up protocol for an asymptomatic gene carrier and his or her family, how to approach counselling, different potential obstacles that may emerge during counselling, and

strategies to overcome them. I also understood more fully the complexity of the care needed by an HD family and how, when properly delivered, such care pays off in a greater sense of belonging and social support for the family. Home visits were a particularly meaningful experience for me, and I am grateful to the families who allowed me to spend time with them.

Although it is difficult to choose highlights of my stay in Manchester, there are three particular areas in which my thinking about HD changed while I was there – and this new thinking will shape my work as a clinical psychologist in Romania going forward:

- The best way to approach counselling of affected or at-risk individuals who wish to have children is by normalising their situation, discussing preimplantation genetic diagnosis and screening, talking about hope for future treatments, and exploring concerns related to having a family if you are affected by HD.
- A continuous, holistic and multidisciplinary approach to care results in a better quality of life for the patient, in the absence of an effective treatment – even when the intervention is purely observational (that is, standard management clinics).
- I gained a better understanding of the supervision process when it comes to genetic counselling, whose goals are to enhance the quality and safety of patient care, and to promote the counsellor's ongoing professional development while protecting them from burn-out.

Last but not least, my experience was greatly enhanced by the amazing group of professionals in Manchester who, through their vast experience in providing services to HD families, and their kindness and inclusiveness, inspired me in many ways.



## New seed funds awarded

EHDN has approved seed funding for a project proposed by neurologist **Jan Lewerenz** of Ulm University to explore whether aminothiols cysteine and glutathione are changed in HD cerebrospinal fluid (CSF).

If so, such changes might indicate cysteine deficiency and/or oxidative stress and provide additional rationale for the treatment of HD with cysteamine, a drug that boosts cysteine levels and that has been approved by the European Medicines Agency for the treatment of other disorders. Oxidative stress is thought to play a role in neurodegeneration, and cysteine is important in biochemical pathways that neutralise pro-oxidants. Moreover, its synthesis seems to be impaired in the HD brain. A recent clinical trial has indicated that cysteamine could be beneficial in HD, but this remains to be confirmed.

A second project approved for seed funding, called CLEAR-HD (Cortical Layer Examination At high Resolution in Huntington's Disease) and led by neurologist **Peter McColgan** of University College London, will use cutting-edge brain imaging techniques to investigate different delivery pathways for huntingtin-lowering therapies that are currently in clinical trials for HD. Some of these therapies are injected into the CSF, where they achieve greatest uptake in the cortex; others are injected into a deep brain structure called the basal ganglia. Using a combination of ultra-high field 7-tesla MRI and magnetoencephalography, McColgan will study these structures at a level of detail that hasn't been possible before.

Finally, neurogeneticist **Marta Biagioli** of the University of Trento has been granted seed funding to explore circ $HTT$ , a highly stable circular RNA molecule derived from the *huntingtin* ( $HTT$ ) transcript. Her group is working on a hypothesis that this class of non-coding RNA plays an important role in the functioning of neurons and could be implicated in neurological disorders. The research could generate novel targets for therapeutic intervention in HD.

**Seed funds are intended to support pilot studies that will eventually kickstart larger projects. The next deadline for applications is 1 November 2020. More information about the programme and how to apply can be found [here](#).**



**Jan Lewerenz**



**Peter McColgan**



**Marta Biagioli**

## Introducing a new EHDN working group

Astri Arnesen, Ruth Veenhuizen and Marleen van Walsem



**Astri Arnesen**



**Ruth Veenhuizen**



**Marleen van Walsem**

Multidisciplinary Treatment and Care is the new name of the working group once called Standards of Care and led by Sheila Simpson and Daniela Rae, as a result of whose tremendous efforts the HD [standard of care](#) was published in 2012. To date, their model remains the best set of guidelines available for managing care for HD patients and their families.

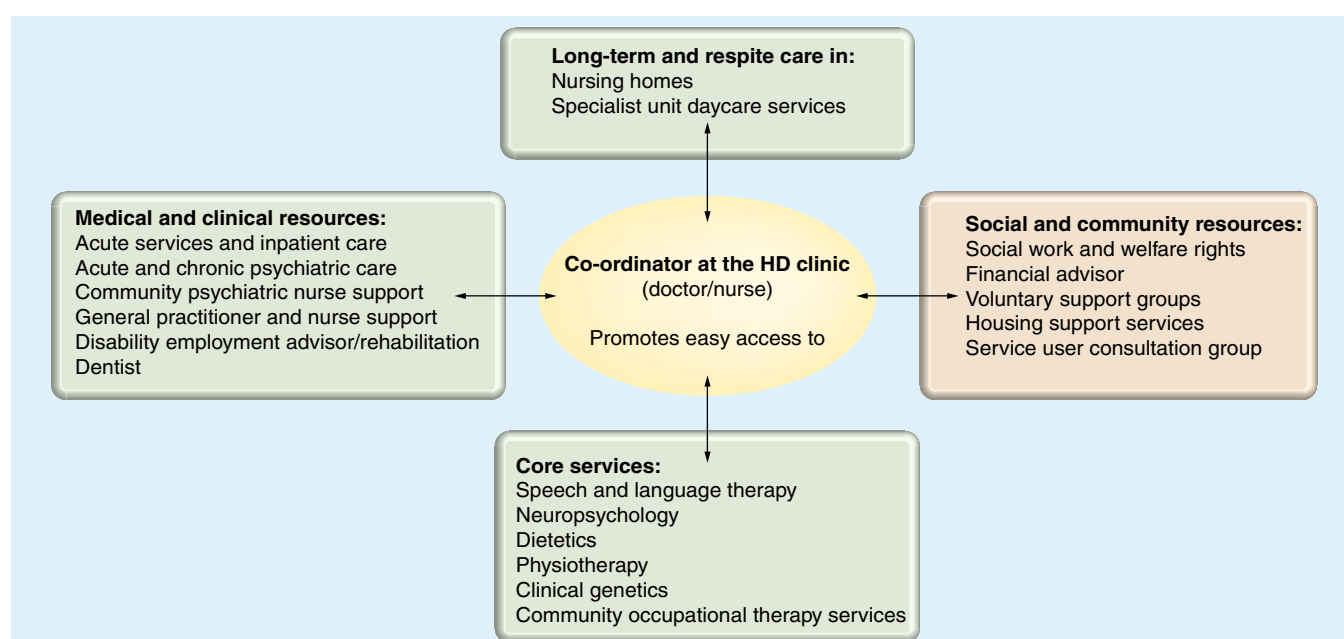
The new group came into being in the autumn of 2019 under lead facilitators Astri Arnesen, President of the European Huntington Association; Oslo-based clinical neuropsychologist Marleen van Walsem; and Ruth Veenhuizen, a Dutch physician working in a nursing home who specialises in HD. The goal of the group is to improve the quality of treatment and care delivered to HD patients and their families, throughout their lives and worldwide.

The first step to realising this goal is to collate national and international guidelines and best practice for professionals from around the world. To do this the group will collaborate closely with other EHDN working

groups. It is well known that HD families need healthcare professionals with knowledge, experience and skills specific for HD, and that they appreciate mutual respect in collaborating with those professionals. Shared language, knowledge and decision-making are key to optimal treatment and patient-centred care. Patient and family perspectives play an important role in the delivery of that treatment and care, and identifying their needs is also one of our goals. Together with the professionals, patients and families will help us identify and then close gaps in HD-related knowledge, experience and skills.

In collaboration with EHDN's Science Think Tank and Executive Committee, the working group will facilitate the development and implementation of task forces which advance these goals.

*If you wish to share your HD care guideline with us, please visit our working group [website](#) to find our email addresses.*



**Managed care pathway depicting the coordinator of HD treatment and care as the central hub of all essential medical, care and social services for patients and family**

## Send us your photos!

**This time our photo is generously provided by Jamie Levey, EHDN's Chief Operating Officer, and it shows Jamie's brother Greg and her daughter Hannah in New York City.**

"The location is very near and dear to us," Jamie says. "It's in the Central Park Conservancy's South Garden, in front of the fountain honouring the children's book author Frances Hodgson Burnett.

It's a place where we have spent much time over the years, with my mom, sister and brother, all of whom were affected by HD. Hannah became a bat mitzvah there in 2014. It's located just in front of Terence Cardinal Cooke Health Care Facility, where Greg is cared for." Jamie adds that Greg contracted Covid-19 in April and recovered, despite his advanced stage of HD. Four weeks later he tested negative for the virus.



*Hannah and Uncle Greg*

## Our photo experiment continues!

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 images in the newsletter. If you have a photo that provides an insight into your daily life, that you think might interest or inspire other EHDN members – or make them think differently about the disease – please send it to us along with a few words explaining who you are and what the image shows:

[newsletter@euro-hd.net](mailto:newsletter@euro-hd.net)





All our wards were turned over to Covid-19 and all our neurological personnel, myself included, essentially became residents in infectious diseases. All other care was suspended.

### ***What is the situation now in Bologna, with Covid-19?***

The number of cases increased throughout March, then plateaued in April. It has been declining since the beginning of May. We are slowly getting back to normal.

### ***Have you stayed well throughout?***

I had Covid-19. I tested positive after a colleague fell sick, and was quarantined for 14 days, but I had almost no symptoms. I'm 65, so I was lucky.

### ***It must have been a difficult time. As a doctor you're trained to face sickness and death, but perhaps not on the scale you've witnessed in recent months.***

We have seen a lot of elderly people die because we weren't able to prevent their deaths. The disease was just stronger than us. That has been very hard, yes.

### ***Did other countries learn enough from Italy's experience?***

No, and I think something should now change on that score. There needs to be far more collaboration in healthcare internationally – if not some unified healthcare mechanism for confronting pandemics, then at least some way of facilitating the sharing of information better.

### ***How did you manage the care of your region's HD families throughout this period, given that all non-Covid-19-related interventions were suspended?***

## **Navigating a hurricane:**

### **Interview with Pietro Cortelli**

Pietro Cortelli is a professor of neurology at the University of Bologna in Italy. He chaired the local programme committee for the 2020 EHDN plenary meeting, which was to be held in his city this September, until Covid-19 put paid to that plan and turned his life and that of Bologna upside down. Here he tells us what the last four months have been like.

### ***What is the connection between your hospital and HD?***

There are three hospitals in Bologna and ours – the Bellaria Hospital, which is part of the university – hosts most of the neurology. We have a big movement disorders centre where we look after around 100 HD families – perhaps 90% of the HD families in the region, Emilia-Romagna – and we are involved in the Enroll-HD study.

### ***What happened to your centre when Covid-19 erupted in the region in early March?***

Mainly by phone, and by telemedicine. Whatever else was happening, they received a call once a month.

### ***How did those families cope, as far as you can tell?***

It was difficult for them. I think the biggest problem for our HD patients was the disruption to their routine, and being confined at home. They are used to being able to take a short walk every day, and to coming to the centre for cognitive and speech therapy, and none of that was possible.

### ***How did you feel about hosting the 2020 EHDN plenary meeting, and how do you feel now that it has been postponed to 2021?***

I was surprised and delighted when EHDN's scientific committee chose us for the site of the 2020 plenary, even though it made sense. The University of Bologna is the oldest university in the world. It was created in 1088, which makes it a few years older than Padua's – though of course the two cities fight over this! We are a major transport hub, ideally situated between the north and the south of Italy, and we have a large student population – 80,000 of them – which helps to make



Bologna a culturally and intellectually vibrant city, as you will discover in 2021! We can replace the meeting to some extent with virtual events, but in my opinion there is no replacing the building of connections and collaborations that happens when scientists meet face-to-face, so I am very glad the meeting will happen eventually.

***Bologna is famous for its Sardines, a grassroots movement born in 2019 to protest against the shift to the right in Italian politics. The movement's name comes from the fact that at its rallies lots of people were packed together like sardines, which is not exactly appropriate behaviour in a pandemic. What are the Sardines up to now – are they still active?***

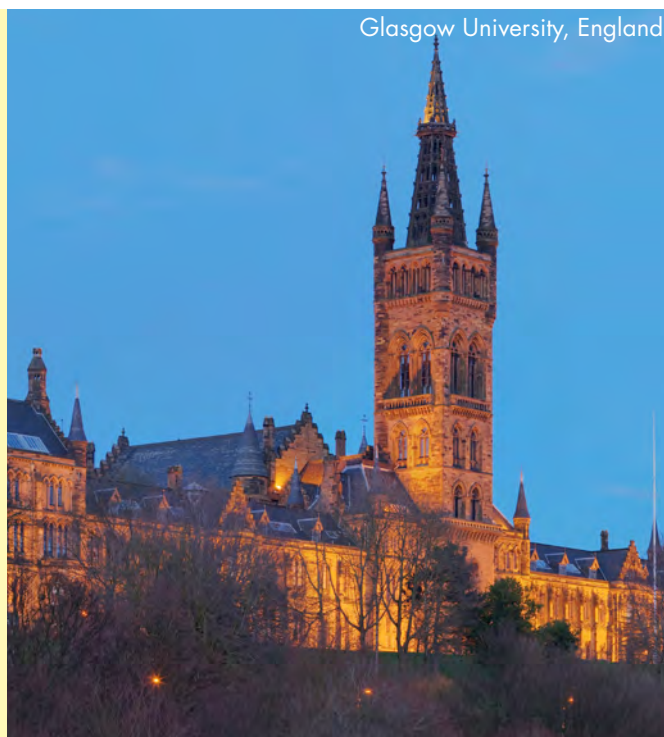
Oh yes! Over the weekend of 16-17 May they organised an online sale of 6,000 potted begonias and aromatic herbs. People paid five euros a pot, and Sardine volunteers made the deliveries on their bikes. The goal was to raise 30,000 euros in 48 hours and the profits went to fund local culture – especially outdoor theatre – which has suffered terribly during the pandemic.

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## **Dates for your diary**

Save the dates for:

- [FENS 2020 Virtual Forum](#), Glasgow, UK, 11-15 July 2020
- [Webinar: "Safeguarding and Huntington's disease"](#), 16 July 2020, 14h UK time
- EHDN plenary "bridging" event, online, 11 September 2020 (details to come)
- [Webinar: "A challenge in neurogenetics: Huntington disease in kids"](#), 15 September 2020, 15-16h CET
- [Webinar: "Clinical practice recommendations for physical therapy for Huntington's disease"](#), 20 October 2020, 15h CET
- [Meeting: "Neurodegenerative diseases: biology and therapeutics"](#), Cold Spring Harbor, USA, 2-5 December 2020
- [EHDN2021 plenary meeting](#), Bologna, Italy, 10-12 September 2021 (details to come)



Glasgow University, England

Photo: Wikipedia