

STRONGER *together* *BETTER* TOGETHER

European Huntington Association



Photo: Orphan People Russia

OCTOBER 4-6 • 2019
RAMADA BUCHAREST CONVENTION CENTER



uniQure



NOVARTIS



Welcome!

Dear participant,

It is with great pride and pleasure we are able to gather the Huntington community here in Bucharest. On behalf of the European Huntington Association board and the Huntington's Disease Association of Romania, I warmly welcome all of you!

One of the most important aim of the European Huntington Association is to connect people. We know from experience that one consequence of Huntington's disease (HD) – on family members, partners, patients and professionals – is loneliness. We want to help everyone affected by the disease to break out of the isolation and receive support from others in the same situation.

Our aim is to facilitate a safe space where we can share our thoughts and experiences. In the different sessions arranged during this weekend, you will hear stories from family members and professionals. You will also get the chance to share your own thoughts in smaller discussion groups and workshops.

We hope all of you will take this opportunity to both learn from the speakers and be active in sharing your thoughts, ideas and experiences.

The name and slogan of this conference “Stronger together- Better together” was chosen to express the importance of this conference. By coming together, we become – not only stronger – but also better. You get better learning from others and don't forget; others get better learning from you!

And remember; Together Everyone Achieves More (TEAM).
So, let's get started TEAM HD!

Astri Arnesen,
President of the European Huntington Association



PROGRAM

FRIDAY • October 4

8:00 Registration / HD on the Move!

If you have registered, join us for a walk!
Together with Rudy Vera, we will meet at the Hotel entrance 8:30.

9:30 Opening

Welcome by Astri Arnesen, President, and her husband and board member Svein Olaf Olsen.

10:10 Welcome

From local authorities and hosts.

10:20 HD in Romania

What is the current situation for people impacted by Huntington's disease in Romania today?

Speaker: Ramona Moldovan

10:50 BREAK

11:20 Taking care of patients

What is good care for me, for my partner and for our patients? Speakers: Anne Lennon Bird, Alexandra Cachia and Fiona Cachia

12:15 How can we contribute in research?

Speakers: Dina de Sousa and Prof. Bernhard Landwehrmeyer

13:00 Talking about HD in the family – our choices and experience as life scientists

Speakers: Paul de Sousa and Johan Oreel
More info: Page 10

TERRA
PLENARY
HALL

TERRA
PLENARY
HALL

13:30 LUNCH



14:30 PARALLEL SESSIONS

1) Family members (exclusively)

Talking about Huntington's disease in the family.
Group discussion.

TERRA 2

2) Romanian participants

What support is available for Huntington's disease?
Moderators: Dr. Radu Constantinescu and Ramona Moldovan. *More info: Page 10*

TERRA 1

3) Professionals

What is good practice? How do we support families to share information? Group discussion. Moderator: Rhona Macleod

MINCU

15:30 COFFEE BREAK



16:00 PARALLEL SESSIONS

Coping with Huntington's disease

1) Professionals

What are the main challenges when working with Huntington's disease? Moderator: Rhona Macleod

MINCU

2) Romanian participants

Moderators: Dr Radu Constantinescu and Ramona Moldovan

TERRA 1

3) Family members (exclusively):

Symptomatic
Gene positive
At-risk or gene negative
Partner or close relatives

ATLAS

MERIDIAN

TERRA 2

TERRA 3

17:00 PARALLEL SESSIONS

Movie

When illness becomes a challenge.

A documentary supported by the Huntington Association of Slovenia. *More info: page 11*

MINCU

Movie

To be Huntington or not.

A documentary supported by Huntington Onlus (Italy).
More info: page 11

ATLAS

Become a study site

Professionals only.

Do you want your clinic to become a study site? During this session you will have the opportunity to sign up as an EHDN Study Site and as a candidate for Enroll-HD Study Site! GSID filling session. Moderator: Dr. Daniel Zielonka. *More info: page 11*

TERRA 2

DOMINO-HD & HEALTHERND

Closed session.

Open only to members of the family and patient representative panel in DOMINO-HD and HEALTHERND.
Speaker: Prof. Bernhard Landwehrmeyer.

MERIDIAN

HD in the Park

Join us for a walk in the park!
The local volunteers will guide us.

HOTEL
ENTRANCE

20:00 DINNER



SATURDAY • October 5

8:30 HD on the Move!

Join us for a walk! It is also possible to run/jog.
Together with Rudy Vera, we will meet at the Hotel entrance
8:30. *More info: page 9*

HOTEL
ENTRANCE

9:30 PARALLEL SESSIONS

Coping with Huntington's disease

How to mobilize your strengths.
Moderators: Rhona Macleod and Mariangels Ferrer

TERRA 1

How to take care of the patient at home

Strategies that allows you to give better care and to
overcome difficulties. Moderator: Helena Soares.
More info: page 11

TERRA 2

Caring for advanced stages patients

Speakers from Atlant care home (The Netherlands) and
Tangkær care home (Denmark).

TERRA 3

Music therapy

What are the benefits of music therapy?
Speakers: Monique van Bruggen and Sunniva Ulstein Kayser.
More info: page 12

MINCU

Sensory stimulation therapy

Learn about sensory stimulation and how to choose
interventions. Speaker: Hanne Kristin Sigmond.
More info: page 12

MERIDIAN

Oral care

Learn more about how to maintain a good oral health.
Speaker: Annette Carlsson. *More info: page 12*

ATLAS

11:00 COFFEE BREAK



11:20 PARALLEL SESSIONS

How to set up and run an association

Speakers: Marco Salvadori, John Eden & Bea de Schepper
The keys to success.

TERRA 1

Predictive testing – why test or why not?

Moderator: Ramona Moldovan

TERRA 2

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MERIDIAN

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ATLAS

13:00 LUNCH



14:00 Sexuality and Huntington's disease

Challenges and solutions. Speaker: Dr. Alzbeta Mühlbäck.

More info: page 13

TERRA
PLENARY
HALL

14:40 PARALLEL SESSIONS

Sexuality and Huntington's disease

Partners

Patients, people at-risk, gene carriers and gene negative

Professionals

MERIDIAN

MINCU

TERRA
PLENARY
HALL

15:30 COFFEE BREAK 

16:00 PARALLEL SESSIONS

Non-drug interventional studies

What is happening right now?

Speakers: Dr Alzbeta Mühlbäck & Pearl van Lonkhuizen about HEALTHE-RND, Monica Busse about DOMINO-HD and John Eden about CARE HD.

More info: page 13

TERRA
PLENARY
HALL

Paediatric and adolescent Huntington disease (HD): new opportunities for juvenile onset HD on horizon

Speaker: Dr. Ferdinando Squitieri

MINCU

17:30 PARALLEL SESSIONS

Soccer Tournament!

Get ready to play! Who is the best team? Is it the EHA Board? Or maybe the Romanian Huntington Association? Time will tell ... *More info: page 9*

HOTEL
ENTRANCE

HEALTHE-RND

Closed session.

MERIDIAN

20:00 DINNER & DANCE

Get ready to dance! Put on your best outfit and dancing shoes.



SUNDAY • October 6

8:30 HD in the Pool!

Join us for a swim!

Together with Rudy Vera, we will meet at the Hotel pool 8:30.

HOTEL
POOL

9:30 Drug trials in HD

What is happening right now?

Use this unique opportunity to hear representatives from the pharmaceutical industry! Learn more about ongoing trials and plans for the future. Moderator: Dr. Ralf Reilmann

9:30 – 9:50 **Roche Pharmaceuticals** with Scott Shobel

9:50 – 10:10 **Wave Life Sciences** with Serena Hung

TERRA
PLENARY
HALL

10:10 BREAK

10:30 Drug trials in HD

What is happening right now? (continues)

Moderator: Dr. Ralf Reilmann

10:30 – 10:50 **uniQure** with Melvin Evers

10:50 – 11:10 **Novartis** with Baltazar Gomez

TERRA
PLENARY
HALL

11:10 Summary

Summary of what we have heard about research and trials.

11:20 Ask your question

During this session, we will have a panel with representatives from the pharmaceutical industry.

We encourage you to ask them your question.

11:50 Round-up and goodbye

12:30 LUNCH



Soccer tournament

Join our soccer tournament on Saturday! Gather your own team of **7 players** and meet us by the Hotel entrance at 17:30. You don't have to be an experienced soccer player – anyone can participate. If you don't want to play yourself, come and cheer together with us!

Can you beat the European Huntington Association Board? We don't think so!



HD on the Move

Why **HD on the Move**? Research on physical activity has shown that being active has several benefits for people affected by Huntington's disease. We therefore encourage you to walk with us every morning!

Our own personal trainer, Rudy Vera, will lead our group through the park on Friday and Saturday. On Sunday we will arrange – for the very first time – **HD in the Pool!** Bring your bathing suit and join us for a swim! (AND, don't forget dinner and dance on Saturday)

Simple tips on how to get active?

www.eurohuntington.org/active-huntingtons

SESSIONS

FRIDAY

12:15 | HOW CAN WE CONTRIBUTE IN RESEARCH?

Speakers: Dina de Sousa and Prof. Bernhard Landwehrmeyer

Clinical research is a key step on the path to developing new therapies — and ultimately, a cure — for Huntington’s disease. In order to achieve the ultimate goal a broad collaboration is needed and family members are crucially important. How can we support research and why is it important? Dina de Sousa will share her personal experiences and thoughts about the importance of taking part in HD research and professor Bernhard Landwehrmeyer will talk about the importance from a clinical and researcher perspective.

13:00 | TALKING ABOUT HD IN THE FAMILY

Speaker: Paul de Sousa and Johan OreeI

Among the challenges of facing HD as a family is talking about it. Raising children; figuring out when and how to enlighten and burden them. Relating to family who variably may not want to know; accepting the costs of differences in circumstances and philosophies. Sharing knowledge with friends; the risks of subsequent communication with others with potential to impact on your family in ways you cannot predict or control. In this presentation I share our choices and experience transitioning from information management to transparency informed by our perspective as life scientists raising a young family abroad.

14:30 | BOALA HUNTINGTON: simptome și tratamente. Experiențe de la un centru specializat

Speaker: Radu Constantinescu and Ramona Moldovan

Trecere în revista a celor mai importante grupe de simptome ale bolii Huntington și ale tratamentelor accesibile. Atât tratamente farmacologice cât și non-farmacologice vor fi prezentate pe scurt împreună cu aspecte generale ale îngrijirii pacienților. În final se va face o prezentare a activității unui centru specializat în tratarea pacienților cu boala Huntington, din orașul Göteborg (Gothenburg), Suedia.

17:00 | DOCUMENTARIES



To be Huntington or not is directed by Gionata Coacci with support from Huntington Onlus, the Italian Network for Huntington Disease. In it we meet young people that have been diagnosed with HD or are at-risk. Hear stories told by young people from Latin America and Italy: parts of the world that are so different, yet they share a common destiny. The film will be screened on Friday in the Atlas meeting room at 17.00

When Illness becomes a challenge is a documentary from Slovenian care homes with HD patients. The documentary follows a volunteer working with Huntington's patients. Her wish is to understand them, to enter their world. She talks to relatives, nursing home staff, doctors, psychologists. The film offer the viewer a new window into the disease. The documentary was supported by the Slovenian Huntington association. The film will be screened on Friday in the Mincu meeting room at 17.00

17:00 | BECOME A STUDY SITE (Professionals)

Speaker: Daniel Zielonka

This GSID-filling session is dedicated to professionals that would like their clinic/site to become an EHDN study site and/or to apply for being an Enroll-HD candidate. During the session you will be able to fill out the documents with the help of Daniel.

Bring your own laptop.

SATURDAY

9:30 | HOW TO TAKE CARE OF THE PATIENT AT HOME

Speaker: Helena Soares

Caring for a Huntington's patient implies a holistic approach making it is necessary to have a multidisciplinary team where the informal caregiver has a fundamental role. The caregiver is the closest person, that in most cases spends 24/7 with the patient. It is the person that knows the patient best and is capable of identifying any alteration of his/her clinical state quicker than anyone else.

This session focuses on teaching and training the informal caregiver with strategies that allows them to give better care at home and overcome some difficulties that are present in

the daily life of the caregiver. These strategies are based on daily activities such as hygiene and comfort, elimination, eating and complication prevention.

9:30 | 11:20 | MUSIC THERAPY

Speakers: Monique van Bruggen & Sunniva Ulstein Kayser

While there is no *cure* for HD yet, all focus should be on *care* for people suffering from HD. In this presentation Sunniva and Monique, both music therapists and PhD-researchers with years of experience with HD-patients, will tell you about the benefits of music therapy. You will also get the opportunity to see footage.

Music therapy is a non-pharmacological intervention, known to improve communication and expressive skills, reducing behavioral problems, leading to a better quality of life in patients with HD. Also, music might take away anxiety and fear for falling and has potential to be a preventive treatment against dysphagia from early stage. Besides that, music can be implemented as a complementary intervention alongside physical therapy and speech/language therapy to delay deterioration in movements and speech.

9:30 | 11:20 | ORAL CARE

Speaker: Annette Carlsson

One of the corner stones for Quality of Life is good oral health. For people with HD there are many problems that affects the oral health. Dry mouth as well as blisters and sores can cause pain and difficulties in eating, speaking and to perform oral care. Toothache and lack of teeth affects even the mental status. Swallowing difficulties increase the risk of aspiration. It is of extra importance to maintain a good oral health and thereby minimize the risk of injurious bacteria reaching the lungs. In this workshop we will discuss how to manage oral care in different aspects. We will also demonstrate several tools that will make oral care easier in daily life.

9:30 | 11:20 | SENSORY STIMULATION THERAPY

Speaker: Hanne Kristin Sigmond

Sensory Integration treatment improves sensory processing and decreases sensory symptoms. The session contains a theory-part and a practical part. The theory seeks to give a better understanding in why the Huntington patient is behaving in certain ways, and what we can do to influence the symptoms. We learn how to choose which interventions. In the

practical part of the session we rehearse simple techniques we can use to give the patient good experiences and hopefully a better daily life.

14:00 | SEXUALITY AND HUNTINGTON'S DISEASE

Speakers: Dr. Alzbeta Mühlbäck

Sexual problems are common in Huntington's disease and contribute to poor quality of life for patients and partners. The loss of desire and dissatisfaction with their sexual life is observed in both genders. Sexual dysfunction is often an ignored aspect, although very relevant and important. This session explores intimacy and sexuality and provides practical suggestions that may contribute to the sexual well-being of patients and their partners and encourages them to talk about the unmet needs.

16:00 | NON-DRUG INTERVENTIONAL STUDIES

Speakers: Dr Alzbeta Mühlbäck & Pearl van Lonkhuizen about HEALTHE-RND, Monica Busse about DOMINO-HD and John Eden about CARE HD.

HEALTHE-RND: The project "European eHealth Care Model for rare neurodegenerative diseases" (HEALTHE-RND) aims at developing an eHealth Care Platform with the focus of the needs of people affected by Huntington's Disease and their companions to improve their quality of life. During the session, the panel members will receive information about the background and development of the planned eHealth module and its clinical implications. The HEALTHE-RND project aims at contributing to achieve the ambitious goal: *It is not the patient who must travel, but the knowledge.*

DOMINO-HD: Consist of a group of European researchers interested in understanding how lifestyle factors influence HD symptoms. They are interested in your views on digital wearable devices and how you might use them during daily life. Please visit their stand to find out how you can get involved in their research during the conference.

Want to know more about all the speakers?

www.eha2019.no/speakers

Photo Exhibition

For the second time, the European Huntington Association is arranging a photo exhibition together with Orphan People (Russia). We would like to sincerely thank everyone that has submitted their photos to us! **The pictures are displayed in the conference room.**

The aim of the photo exhibition is to give people from the Huntington community an opportunity to express themselves with the help of a visual channel. In the fight against stigma, fear and isolation we encourage people to give others a sneak-peak into their lives through the camera lens.

We hope you enjoy the exhibition! And we hope that you will send us your picture for next year exhibition.



Winning photo 2018: The picture of Mark was submitted by Jackie with the title: *"For animals Huntington's disease is no barrier"*

Posters

The poster sessions give each conference participant the opportunity to see the posters of their colleagues, friends and institutions on the latest topics of the HD community.

Posters are available for daily viewing and authors will be present and available to discuss their work and answer questions. Each participant will vote for the best three posters during the conference and the winners will be announced at the gala dinner on Saturday, October 5, 2019.



Huntington Song

Olivia Sawano was asked by EHA to write a song for the Huntington community. She came up with **North Star - HD 8890**:

"It was in the evening on the 22nd of December 2011 when we learned that our father had Huntington's disease (HD). We stepped outside on the balcony to look at the stars. There are no statistics but it's safe to say that nobody ever felt worse after looking at the stars.

When I was collecting ideas for the song, I found out that "HD" was also an abbreviation for a star catalogue. It is named after Henry Draper who lived at the same time as George Huntington.

I think it is beautiful that now, whenever I see the abbreviation HD, it does not just make me think about Huntington's disease but also about stars."

1.
North Star
Shining so bright
Twinkeling in the night

North Star
Glowing so gently
Guiding us from afar

We keep on looking back
We keep on looking ahead

434 lightyears away
When did we last look up?

(Look up, look up)

2.
Night sky
Blanket of stars
Soothing our souls in the dark

Starlight
Wise and old
So many tales to be told

Sometimes we can't forgive
Sometimes we can't forget

434 lightyears away
Reach out and make a wish

(Reach out, reach out)

3.
North Star
One day you'll be gone
But your light travels on and on

And when it hits us
Like a note from the past
Like a gift that will last forever

We're gonna be alright
We're gonna be ok

'Cause 434 lightyears away
We spread our light to shine on

(Shine on, shine on)



Fun Fact:

Henry Draper, who invented the star catalogue, died at the age of 44 from just having a cold.

Conclusion: *Life expectance with Huntington's disease today is higher than life expectance of the people living at the time of Henry Draper & George Huntington.*

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Thank you for supporting the Huntington community!