



European Conference
on Huntingtons disease

STRONGER *together*



September, 22.-24. 2017
Hotel Ramada - Sofia - Bulgaria

Day 1

Friday September 22

10.00-16.00	<i>Registration</i>
14:00-15:30	Pre-session: Meet the pharma Use this unique opportunity to meet representatives from the pharma industry: Roche, Wave, Ionis, Uniqure and potentially more companies. In this informal session you will hear about ongoing clinical trials and plans for the nearest future . Our aim is to elaborate the communication between the HD community and the pharma industry.
14.00-15.30	Bulgarian Pre-session: Research update The most promising pathways to HD treatment. ^w /Juliana Bronzova
16.00-16.30	<i>Opening & Welcome</i>
16.30-17.15	HD in Bulgaria Seen from the view of a family member, a neurologist, and a health carer ^w /Dr. Sahka Zheliazkova, Hristina Dimitrova and Nataliya Grigorova
17.15-17.35	Coffee break
17.35-18.15	What does it mean to grow up in an HD family? What are the children's needs? ^w /Ass. Prof. Melinda Kavanaugh
18.30-19.30	Parallel sessions: dialogue sessions / workshops <i>NB! See next page for more information</i>
20:00	Dinner Buffet served at the Hotel

Parallel sessions, Day 1:

Dialogue sessions / Workshops

18.30-19.30

1. Genetic testing

Genetic testing is a serious and demanding decision. Dr. Mühlbäck has met many HD affected who consider to test or not. What are the **implications**: *is it right or wrong for me to know my genetic status?*

Dr. Mühlbäck will also talk about the international guidelines for test procedures and the main differences between presymptomatic and diagnostic testing.

You will be able to ask questions, share thoughts and experiences.

^w/Dr. Alzbeta Mühlbäck, neuropsychiatrist

2. The importance of physical activity

For many years the benefits of physical activity in HD mice has been known. Lately there has been performed several clinical trials with HD patients: *how can systematic activity improve health condition and quality of life in HD?*

Susan O'Neill is an experienced physiotherapist at the Bloomfield Hospital near Dublin and Dr. Juliana Bronzova has been focusing on the "physical treatment" for a long time.

Physical activity is the most efficient "pill" for HD known today. So we should take it, shouldn't we?

^w/Susan O'Neill & Dr. Juliana Bronzova

3. Frustration in HD:

Strategies to lower the level of frustration for patients & carers

HD families and professional carers often experience a lot of frustration. Where does this frustration come from and how can we deal with it?

It is possible to reduce the level of frustration through understanding the cognitive mechanisms that might lie underneath: we can think about and handle things in a different way. Maybe this can make us cope the situation better?

^w/Dr. Dirk Liessens, psychiatrist

4. Clinical (patient)trials ABC for non scientists

We are all waiting for a breakthrough in the search for treatment. *How are the trials being conducted? And why does it take so long from an idea to a fully approved drug?*

Dr. Squitieri and Reilman are principal investigators in several HD clinical trials and will walk us through the trial "jungle".

^w/Dr. Ferdinando Squitieri & Dr. Ralf Reilman

Day 2

Saturday September 23

08.30 - 09.15	<i>HD on the move</i> Go for a walk in the morning! Start from the hotel entrance at 08.30. The organizers will be there and walk together with you. <i>Bring good shoes and water.</i>
09.30- 11.30	Parallel sessions: <i>working groups</i> <i>NB! See next page for more information</i>
11.30- 12.00	Coffee break
12.00- 12.45	How can we collaborate to be “Stronger together”? Developing a HD service from the ground up ^w /Dr. Jennifer Hoblyn
12.45- 13.15	<i>Genetic testing – best to know or not?</i> Who needs to know and how should testing be done in order to make sure it's beneficial? ^w /Dr. Alzbeta Mühlbäck
13.15- 14.15	Lunch
14.15- 15.00	<i>Can we delay age-of-onset? About lifestyle influence.</i> ^w /Prof. Monica Busse & Beth Ann Griffin
15.00- 15.15	Short time-out: Physical activity ^w /Rodolfo Vera
15.15- 16.00	<i>Clinical trials – how to measure if treatments work.</i> Challenges in HD research ^w /Dr. med Ralf Reilmann & Filipa Júlio
16.00- 16.15	Coffee break
16.15- 17.30	Parallel sessions: <i>discussion groups</i> <i>NB! See page 6 for more information</i>
17.30- 18.15	Yoga and Mindfulness in practice A way to take better care of yourself ^w /Amy Merkel
20.00	Dinner Gala Dinner at the hotel with music and dance

Parallel sessions, Day 2:

Working groups

09.30-11.30

We encourage you to bring questions, thoughts and experiences to the session.
We can all learn from each other. The experts doesn't have all the answers.

1 Personality – does HD change it or disguise it?

Jimmy Pollard has been head of a care facility for HD patients and is the author of the book: "Hurry up and wait!" Mr. Pollard will walk us through how HD can make people look angry, tired or bored. Sometimes we misunderstand the signals but if we look closely we can see the ones we love through Huntington's disease—or Huntington's disguise. Let's examine the disguise together.

^w/Jimmy Pollard

2 Juvenile Huntington

Juvenile Huntingtons Disease (JHD) is rare and sometimes we tend to forget this extraordinary severe condition in HD conferences. Dr Squitieri will talk about the typical symptoms in JHD and how it best can be treated.

^w/Dr. Ferdinando Squitieri

3 Nutrition, eating and swallowing – needs, challenges and solutions

Nutrition and keeping a healthy weight can be a big challenge for HD patients and their carers. Dr. Klempir and Nuzzi have been focusing on this key area in HD and will share their knowledge about how HD patients can be assisted in the best way

^w/Dr. Klempir & Angela Nuzzi

4 Dealing with psychiatric disturbances and disorders

How can psychiatric illness in HD be treated in the best way? HD represents a huge complexity and sometimes treatment must be out of the mainstream box to be efficient for HD patients.

^w/Dr. Alzbeta Muelhbaeck

5 Minding your Mental Wellbeing in HD

Living with HD in your family or as a professional carer is often a stressful situation. How can you take care of yourself and at the same time take care of the people around you?

^w/Dr. Andrea Higgins

Parallel sessions, Day 2:

Discussion groups

16.15-17.30

In these groups we want to gather people with the same background/position in HD. The sessions are supposed to work as support groups where one mediator helps with the dialogue. You are encouraged to share thoughts and experiences, but you are also allowed to just listen. Participate to the degree you are comfortable with.

Group 1: For people at-risk or gene positive/negative

Group 2: For partners to at-risk or gene positive/negative

Group 3: For people with HD symptoms

Group 4: For partners to HD symptomatic

Group 5: For professional care givers or health givers

In this group we want you to share the challenges and successes you have experienced in your work with HD families.

Group 6: Bulgarian session

Psycho-social support for families with rare diseases in Bulgaria - mission possible

In this group you are going to look at the opportunities for social and rehabilitation services in Sofia. It will also be discussed how the services can be improved.

^w/Nataliya Grigorova

Day 3

Sunday September 24

08.30-09.15	<p><i>HD on the move</i></p> <p>Go for a walk together with Rodolfo Vera! We encourage all participants to join us for a walk. We'll meet at the hotel entrance at 8.30.</p> <p>There will be two options: one for the fast ones (run or walk) and one for the slower ones (walk for pure pleasure with medium pulsrate). Remember to bring good shoes. Mr Vera will lead us with all his enthusiasm.</p>
09.45-10.20	<p><i>Huntingtin lowering therapies - an update</i></p> <p>Huntingtin lowering therapies are among the most promising in the search for an HD treatment. Prof. Tabrizi is principal investigator for one of the trials.</p> <p><i>What are the trials about and what are the perspectives?</i></p> <p>^w/Prof. Sarah Tabrizi</p>
10.20-11.15	<p><i>An overview over research and clinical trials</i></p> <p>There are several pathways to treat HD. What trials are ongoing and what are the perspectives for the coming years?</p> <p>^w/Prof. Bernhard Landwehrmeyer</p>
11.15-11.35	<p><i>The importance and the opportunities of Enroll-HD</i></p> <p>Enroll-HD is a worldwide observational study for Huntington's disease families. It monitor how the disease appears and changes over time in different people. It is open to people who either have HD, are at-risk or is a spouse/partner of someone at risk. <i>Why is this study so important?</i></p> <p>^w/Tim McLean</p>
11.35-12.00	<p><i>Summarize and goodbye</i></p>
12.00	<p>Lunch</p>



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