



Stronger together!

September 22.-24. 2017

Hotel Ramada, Sofia, Bulgaria

European Conference on Huntingtons Disease

Friday 22nd of September 2017

12.00 -16-00	Registration
14.00-15.30	Bulgarian Preession: <i>Research update – most promising pathways to HD treatment,</i> Juliana Bronzova
16.00-16.30	Opening and welcome
16.30-17.15	<i>HD in Bulgaria</i> seen from a family member, a neurologist, and a health carer, Dr. Sahka Zheliazkova, Hristina Dimitrova, Nataliya Grigorova
17.15-17.35	Coffee break
17.35-18.15	<i>What does it mean to grow up in an HD family? What are the childrens needs?</i> Ass. Prof. Melinda Kavanaugh
18.30-19.30	<p>Parallell sessions – dialogue sessions/work groups:</p> <p>1) <i>Genetic testing</i> - Dr. Alzbeta Muelhbaeck, neuropsychiatrist</p> <p>Genetic testing is a serious and demanding decision. Dr Muelhbaeck has meet 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 Muelhbaeck will also tell about the international guidelines for test procedures, the main differences between presymptomatic and diagnostic testing. The participants will be able to ask questions, share thoughts and experiences.</p> <p>2) <i>The importance of physical activity</i> - Susan o`Neill, senior physiotherapist and dr Juliana Bronzova</p> <p>For many years the benefits of physical activitiy in HD mice has been known. Lately there has been performed several clinical trials with HD patients being physically active. 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, Ireland. Dr Juliana Bronzova has been focusing on the "move pill" for a long time. Physical activity is the most efficient treatment for HD we have today. So we should take it, shouldn`t we?</p>

3) *Frustration in HD – strategies to lower the level of frustration both for HD patients and carers* - Dr. Dirk Liessens, psychiatrist
 In HD families and among professional carers we often experience a lot of frustration. Everyday events suddenly gets very complicated. Where does this frustration come from and how can we deal with it? We believe it is possible to reduce the level of frustration through understanding the mechanisms that may be underneath. We may do things in a different way and we may think about the situations in a different way to make us feel better and act better.

4) *Clinical (patient) trials ABC for non scientists* – Dr Ferdinando Squitieri and Dr Ralf Reilman
 We are all waiting for a breakthrough in the search for treatment. How are the trials being conducted? Why is it taking so long from the idea to approved drug? Dr Squitieri and Reilman are principal investigators in several HD clinical trials.

Dinner at the hotel (Buffet style)

20.00

Saturday 23rd of September 2017

HD on the move

8.30-09.15

We know that physical activity is good for all and particularly good for HD affected. That's why we encourage you to go for a walk in the morning. Start from the hotel entrance at 8.30. The organizers will be there and walk together with you. Bring good shoes and some water.

Parallell sessions: working groups:

We encourage the participants to bring questions, thoughts and their experience to the session. We want to learn from each other. The experts doesn't have all the answers.

1) *Personality – does HD change it or disguise it?* - Jimmy Pollard

Pollard has for decades been head of a care facility for HD patients. He is the author of the book: "*Hurry up and wait!*" Some of the physical features of HD combine with some of its cognitive features to create the appearance that one may be angry, tired, not interested or bored. Although we may know those we love so closely, even we can be mistaken! By looking closely at all these features we can more easily see the one we love through Huntington's Disguise! Let's examine the disguise together and talk about new ways to describe it to others.

9.30-11.30

2) *Juvenile Huntington* – Dr Ferdinando Squitieri

JHD is very 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.

	<p>3) <i>Nutrition, eating and swallowing – needs, challenges and solutions</i> – Dr Klempir and Angela Nuzzi 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. Eating is a major part of ones quality of life – being afraid to eat is devastating.</p> <p>4) <i>Dealing with psychiatric disturbances and disorders</i> – Dr Alzbeta Muelhbaeck, neuropsychiatrist 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. Dr Muehlbaeck is running an HD clinic and as a neuropsychiatrist her experience in this field is highly valuable.</p> <p>5) <i>Minding your Mental Wellbeing in HD</i> – Dr.Andrea Higgins, neuropsychologist Living with HD in your family or as a professional carer is often a stressfull situation. How can you take care of yourself and at the same time take care of the people around you? We need to recognize our own needs to be a good family member or professional. What feelings are common and somehow demanding in your situation and how can you deal with it in a good way?</p>
11.30-12.00	Coffee break
12.00-12.45	<p>Plenary sessions</p> <p><i>How can we collaborate to be "Stronger together" – developing a HD service from the ground up.</i> Dr. Jennifer Hoblyn, Clinical Director, Bloomfield Hospital, Ireland At Bloomfield they started to provide services for HD families a few years ago. They made it happen despite difficult economic frames. What factors are crucial to make this possible?</p>
12.45-13.15	<p><i>Genetic testing – best to know or not?</i> Dr. Alzbeta Muelhbaeck A difficult and demanding choise – who needs to know and how should testing be done in order to make sure it`s beneficial?</p>
13.15-14.15	Lunch
14.15-15.00	<p><i>Can we delay age-of-onset? About lifestyle influence.</i> Prof. Monica Busse We know with great certainty that the number of CAG repeats is one among several factors that influcene age of onset and symptom development in HD. So, which lifestyle factors are influencial and how do they influence health status in HD?</p>
15.00.15.15	<p>Small time-out with physical activity, Rodolfo Vera Mr Vera comes from an HD family he is a teacher in physical activity and engaged in HD community.</p>
15.15-16.00	<p><i>Clinical trials – how to measure if treatments work. Challenges in HD research,</i> Dr. med Ralf Reilmann and Filipa Júlio, neuropsychologist HD symptoms often develops slowly and are difficult to measure. In trials it`s a challenge to measure if treatment has effect or not. New methods are underway and we need those to perform more efficient and valid trials.</p>
16.00-16.15	Coffee break

16.15-17.30	<p>Parallell sessions – discussion groups: In these groups we want to gather people with the same background/position in HD. The session is a kind of support group where one mediator helps moving the dialogue forward. The participants are encouraged to share thoughts and experiences, but you are also allowed to be mostly a listener if that is the right thing for you.</p> <p>1)At-risk/gene positive or negative</p> <p>2)Partner to at-risk or gene positive/negative</p> <p>3)HD Symptomatic</p> <p>4)Partner to HD symptomatic</p> <p>5)Professional care- or healthgiver. In this group we expect you to share the challenges and successes you have experienced in your work with HD families.</p> <p>Plenary session</p>
17.30-18.15	<i>Yoga and Mindfulness in practise - A way to take better care of yourself,</i> Amy Merkel, yoga teacher from an HD family
20.00	Gala Dinner at the hotel with music and dance
Sunday 24th of September	
8.30-9.30	<i>HD on the move</i> – walk and fun with Rodolfo Vera We encourage all participants to join us in this walk. We meet at the front door of the hotel at 8.30. There will be two options: one for the fast ones (run or walk) and one for the slower ones (walk for pure pleasure and with medium pulsrate) Remember to bring good shoes. Mr Vera will lead us all with his enthusiasm.
9.45-10.20	Plenary sessions <i>Huntingtin lowering therapies - an update,</i> Prof. Sarah Tabrizi, These therapies are among the most promising in HD. Prof. Tabrizi is principal investigator for one of the trials. What are the trials about and what are the perspectives?
10.20-11.15	<i>An overview over research and clinical trials,</i> Prof. Bernhard Landwehrmeyer There are several pathways to treat HD. What trials are ongoing and what are the perspectives for the coming years?
11.15-11.45	Summarize and goodbye
12.00	Lunch