



## **Let Us Talk: Building up the communication skills of HD professionals to empower HD families**

Web-based communication skills training course that aims to educate and guide HD professionals on how to use effective communication skills to optimize their relationship with HD families.

### **1<sup>st</sup> Session – January 15<sup>th</sup> 2022 (Saturday), 15:00-19:00 (Moscow Time)**

<b>Topic</b>	<b>Contents</b>	<b>Speakers</b>
Introduction 15:00 – 15:15	Presentation of all the attendees, the course goals, structure and main contents 15:00 – 15:15	Astri Arnesen [President of the European Huntington Association]
HD in Russia 15:15 – 16:15	Presentation about the Russian HD Association 15:15 – 15:35	Marina Tretyakova [President of the Orphan People]
	Presentation about the Moving Forward Project in Russia 15:35 – 15:55	Zaynab Umakhanova [Project Coordinator of Moving Forward in Russia]
	Presentation about the Moving Forward Survey Results in Russia 15:55 – 16:15	Filipa Júlio [Project Manager of the European Huntington Association]
<b>Q&amp;A and Communication Skills Questionnaire – 16:15 – 16:40</b>		
<b>Break – 10 minutes</b>		
<b>Topic</b>	<b>Contents</b>	<b>Speakers</b>
HD Basics 16:50 – 18:50	Screening of video about Ekaterina Limaeva 16:50 – 17:00	Ekaterina Limaeva [Family Member – Russia]



Video with testimony from Ekaterina Limaeva 17:00 – 17:10	Ekaterina Limaeva [Family Member – Russia]
Huntington's Disease - Clinical Features, Diagnosis, Therapeutic Approaches 17:10 – 17:40	Sergey Klyushnikov [Neurologist; PhD; leading researcher of Neurogenetics Department, Research Center of Neurology; Member of the Russian Society of Neurologists and Medical Geneticists, Movement Disorder Society, and European Huntington's Disease Network (EHDN)] – Russia
Recognising and Managing Changes of Behaviour and Mental State in HD 17:40 – 18:10	Professor Hugh Rickards MD FRCPsych [Consultant in Neuropsychiatry; Honorary Professor of Neuropsychiatry, University of Birmingham; Honorary Consultant University Hospital Birmingham; Chair of Executive Council of the Huntington's disease Association (England and Wales)] – UK
Video with testimony from Anne Elizabeth Magnusson 18:10 – 18:20	Anne Elizabeth Magnusson [Family Member – Sweden]
Video with testimony from Saija Ristolainen-Kotimäki 18:20 – 18:30	Saija Ristolainen-Kotimäki [Family Member – Finland]
Screening of video about Nikita Sharov 18:30 – 18:40	Nikita Sharov [Family Member – Russia]
Video with testimony from Alevtina Sharova 18:40 – 18:50	Alevtina Sharova [Family Member – Russia]
<b>Q&amp;A and Poll about the Session Topic – 18:50 – 19:00</b>	



**2<sup>nd</sup> Session – January 22<sup>nd</sup> 2022 (Saturday), 15:00-19:00 (Moscow Time)**

Topic	Contents	Speakers
HD Genetic Testing and Communication 15:00 – 16:50	Screening of the Documentary “Absolute Beginners” 15:00 – 15:45	
	Ethics of Genetic Testing for Huntington's Disease 15:45 – 16:05	Izhevskaya Vera Leonidovna [Doctor of Medicine; Deputy Director for Science at N.P. Bochkov Research Centre for Medical Genetics; Chairman of the Russian Society of Geneticists] – Russia
	Debate 16:05 – 16:50	Alice Rivières [Alice tested positive for Huntington's disease. In 2012, with Valérie Pihet, she founded Dingdingdong – Institute for the coproduction of knowledge about Huntington's Disease, a team of French and Belgium artists and researchers in social science] – France/Belgium
	Ramona Moldovan [Professor of Clinical Psychology and Genomics, University of Manchester; Academic Appointment, Babeş-Bolyai University] – Romania/UK	
Mariangels Ferrer-Duch [Clinical Psychologist; Family Therapist and Narrative Therapist; Master of Narrative Therapy and Community Work - Dulwich Centre/University of Melbourne; member of the faculty of the Institute of Narrative Therapy; Honorary Teaching Lecturer in Evolution and Genomic Sciences of the School of Biological Sciences, University of Manchester] – UK		
Izhevskaya Vera Leonidovna		



		[Doctor of Medicine; Deputy Director for Science at N.P. Bochkov Research Centre for Medical Genetics; Chairman of the Russian Society of Geneticists] – Russia
<b>Break – 10 minutes</b>		
Topic	Contents	Speakers
HD Clinical Care and Communication 17:00 – 18:40	Video with testimony from Ainur Shakirov 17:00 – 17:10	Ainur Shakirov [Family Member – Russia]
	Video with testimony (to be confirmed) 17:10 – 17:20	[Family Member – Russia]
	Video with testimony from Rob Haselberg 17:20 – 17:30	Rob Haselberg [Family Member – The Netherlands]
	Video with testimony from Matt Ellison 17:30 – 17:40	Matt Ellison [Family Member – UK]
	The Whole is Greater than the Sum of the Parts: Long-term Benefits of the HD clinic to the HD community 17:40 – 18:10	Martha Nance [Neurologist; Geneticist; Director of the HD Center at Hennepin Healthcare, Minnesota; Member of the EHDN Scientific and Bioethics Advisory Committee; Member of the Advisory Committee for JOIN-HD; Winner of the Huntington Study Group's Lifetime Achievement Award] – USA
Huntington Disease: Difficult Topics to Discuss at the Doctor's Office 18:10 – 18:40	Yury Seliverstov [MD; PhD; Assistant professor, neurologist of movement disorders and neurodegenerative disease; Research Center of Neurology and Kazaryan Center of Epileptology and Neurology, Moscow; Member of the MDS-ES Educational Committee, EAN Scientific Panel for Movement Disorders, AAN, and EHDN] – Russia	
<b>Q&amp;A and Poll about the Sessions Topics – 18:40 – 19:00</b>		



### 3<sup>rd</sup> Session – January 29<sup>th</sup> 2022 (Saturday), 15:00-19:00 (Moscow Time)

Topic	Contents	Speakers
Communication Challenges 15:00 – 16:30	Verbal Communication in HD (provisional title) 15:00 – 15:30	Alzbeta Mühlbäck [Neuropsychiatrist; Genetic consultant; Member of the EHDN Executive Committee; Principal Investigator in several HD studies] – Germany
	The Nonverbal Clues That Reveal Cognitive Challenges 15:30 – 16:00	Jimmy Pollard [Special Education Teacher; former Nursing Home Administrator; Speaker on several HD-related topics for the CHDI Foundation] – USA
	Peculiarities of Psychiatric Care and Psychotherapy for Patients with Huntington's Disease 16:00 – 16:30	Bibigul Dranitsina [PhD; Psychiatrist; Sex-therapist; Psychotherapist; Research scientist at Moscow Research Institute of Psychiatry] – Russia
<b>Q&amp;A and Poll about the Session Topic – 16:30-16:50</b>		
<b>Break – 10 minutes</b>		
Topic	Contents	Speakers
Communication Tips 17:00 – 17:30	When the Family Member is a Doctor 17:00 – 17:30	Mara Andrade [Master's Degree in Medicine; Family Medicine Specialization; GP at the Urgent Care Department at Pedro Hispano Hospital, Matosinhos; volunteer for Médecin du Monde; Family Member] – Portugal
Producing Guidelines for Communication between HD professionals and HD families 17:30 – 18:20	Three Working Groups	Moderators: Julia Oblitsova [Member of the Orphan People; Member of the Moving Forward Project Team in Russia]



		Zaynab Umakhanova [Project Coordinator of Moving Forward in Russia] Marina Tretyakova [President of the Orphan People]
Global Summary of the Guidelines 18:20 – 18:50	Presentation about the main ideas coming out of the working groups	Designated spokesperson of each working group
<b>Closing Remarks – 10 minutes</b>		
<b>One Week Later: Delivery of Course Certificate, Communication Skills Questionnaire and Short Survey about the Course</b>		