



## The Inaugural Conference of Huntington Disease Society of India (HDSI)

Venue: 4<sup>th</sup> Floor, M V Govindaswamy building NIMHANS, Bengaluru, India

### PROGRAMME

<b>Day 1: 16<sup>th</sup> August 2019</b>	
8.30 am onwards	Registration
<b>Inauguration and Lighting of the Lamp</b>	
9.30 -10.40am	Invocation/Director's address /HOD address/ Inauguration of HDSI Address by Founder member of HDSI : Dr Nayana Shah HD: the international perspective : Mr Svein Olaf Olsen HD experience in GCAT clinic : Dr Sanjeev Jain
<i>Tea Break (10.40-11.00AM)</i>	
<b>Clinical Services and care for HD in India</b> <i>Chairs: Dr Sanjeev Jain &amp; Dr Ravi Yadav</i>	
11.00-11.50am	HD experience at the NIMHANS Clinic : Dr Ravi Yadav HD experience in Kolkata : Dr Hrishikesh Kumar
<b>Present and future prospects for HD treatment</b> <i>Chairs: Dr Vijay Chandru &amp; Prof Sharat Chandra</i>	
12.00- 12.50pm	Clinical trials - Nuts and bolts: Dr Ralf Reilmann Open platform for Rare diseases: Dr Vijay Chandru
1.00-1.30pm	Update on treatment guidelines for HD Panel Discussion : Dr Ralf Reilmann, Dr Sanjeev Jain, Dr Pramod Pal & Dr Hrishikesh Kumar
<i>Lunch break with posters(1.30-2.30PM)</i>	
<b>HD diaries</b>	
2.30-4.30pm	Compiled narrative of patient experiences : Ms Bhakti and Mr Vikas Bhat <i>Panel : Ms Astri Arnesen, Dr Hrishikesh Kumar, Dr Nikhil Ratna</i>
<i>Tea break (4.30-5.00 PM)</i>	
<b>Patient narratives contd.</b> <i>Chairs: Dr Nikhil Ratna and Dr Meera Purushottam</i>	
5.00-5.40pm	The European HD family experience: Ms Astri Arnesen & Mr Svein Olaf Olsen Caring for a patient with dementia: Wing Cmdr Sabharwal



A Blue Ribbon Rare Disease Event



<b>Day 2: 17<sup>th</sup> August 2019</b>	
9.00 am-onwards	Registration
<b>Genetics of Huntington's disease</b>	
<i>Chairs: Dr Ralf Reilman, Dr. Gautham Arunachal &amp; Dr Sanjeev Jain</i>	
9.30-9.50 am	HD genetics, history and geography; the road ahead : Dr Sanjeev Jain
9.50-10.40 am	Introduction to Genetic Diagnostics in HD: Dr Meera Purushottam Social and Ethical issues in genetic testing of HD: Dr Meenakshi Bhat Pre implantation genetics, prenatal counseling for HD: Dr Sridevi Hegde Multi-gene Testing & Diagnostic Yield: Dr. Ashraf Mannan
<i>Tea break (10.40-11.00am)</i>	
<b>Support for HD</b>	
<i>Chair: Dr Meera Purushottam</i>	
11.00-12.20pm	Outcome and co-morbidities in HD : Dr Nitish Kamble HD rehabilitation and care: Dr B K Yamini & Dr Selva Ganapathy
	IHA organization and support for HDSI : Mr Svein Olaf Olsen
	EHA – model/insights for patient support group: Ms Astri Arnesen
12.30-12.55pm	Lessons from the HD clinic- India & abroad : Dr Nikhil Ratna
1.00-1.30pm	Question answer session
<i>Lunch break with posters (1.30-2.30PM)</i>	
2.30-2.50pm	Targeting mutant huntingtin toxicity by DNA aptamers and small molecules: Dr Ravi Vijayvargia
3-3.20pm	Travails and Victories of Thalassemia Patient Groups: From Disability Bill to Free Medicines : Dr Namitha Kumar
3.20-3.40pm	HD treatment – is Insurance available? : Ms Vijayalakshmi Magal
3.40-4.00pm	Questions and Answers
4.30-5.00pm	Concluding Session
<i>High tea for all participants (5.00-5.30pm)</i>	
5:30-6:30pm	HDSI, aims, objectives, road map ahead (HDSI board members and advisors)



A Blue Ribbon Rare Disease Event



### List of Speakers:

- Dr Ralf Reilmann, *Founding director, George-Huntington-Institute, Muenster, Germany*
- Dr Nayana Shah, *Director, Manthan- Centre for Human and Organization Development, Ahmedabad*
- Mr Svein Olaf Olsen, *President, The International Huntington's Association, Norway*
- Ms Astri Arnesen, *President, European Huntington Association, Norway*
- Dr Sanjeev Jain, *Professor, Molecular Genetics Laboratory, Dept of Psychiatry, NIMHANS*
- Dr Pramod Pal, *Professor, Department of Neurology, NIMHANS*
- Dr Hrishikesh Kumar, *Head, Department of Neurology, Institute of Neurosciences, Kolkata*
- Prof Vijay Chandru, *Honorary Director, OPFORD Foundation and CHET, Bengaluru*
- Dr Sridevi Hegde, *Head, Department of Medical Genetics, Manipal Hospital, Bengaluru*
- Prof H Sharat Chandra, *Honorary Director, Centre for Human Genetics, Bengaluru*
- Dr Meenakshi Bhat, *Faculty, Centre for Human Genetics, Bengaluru.*
- Dr Ashraf U Mannan, *Head, Germline Reporting, Strand Life Sciences, Bengaluru*
- Dr Ravi Yadav, *Professor, Department of Neurology, NIMHANS*
- Dr Nitish Kamble, *Assoc Professor, Department of Neurology, NIMHANS*
- Dr B K Yamini, *Asst Professor, Department of Speech Pathology, NIMHANS*
- Dr V Selva Ganapathy, *Senior physiotherapist, Department of Physiotherapy*
- Dr Namitha Kumar, *Hon. Research Director, Centre for Health Ecologies and Technology (CHET)*
- Dr Meera Purushottam, *Senior Scientific Officer, Molecular Genetics Lab, Dept of Psychiatry*
- Dr Nikhil Ratna, *Doctoral Student, Department of Clinical Neurosciences, NIMHANS*
- Dr Ravi Vijayvargia, *Associate Professor, Department of Biochemistry, M .S. University of Baroda*
- Dr Gautham Arunachal, *Asst Professor, Department of Human Genetics, NIMHANS*
- Retd. Wing Cmdr Dharam Paul Sabharwal
- Ms Vijaylakshmi Magal, *Insurance Consultant and Trainer, Bengaluru*

