Blue Ribbon Rare Diseases Symposium 2018

Centre for Health Ecologies and Technology (CHET)
International Institute of Art, Culture and Democracy (IIACD)
March 14, 2018 (10 am – 5:30 pm)

The Centre for Health Ecologies and Technology (CHET) at IIACD, Bangalore presents its third annual Blue Ribbon Rare Diseases series of events, which includes the Blue Ribbon Rare Diseases Symposium 2018 at the National Gallery of Modern Art, Bengaluru. This symposium is jointly organized under CHET's Medical Humanities and Bioethics Initiative (MHBI) and IIACD's Autism and Rare Disease Awareness (ARDA) outreach programme.

The Blue Ribbon Rare Diseases symposium 2018 as well as our other annual Blue Ribbon Events has drawn inspiration from the Blue Denim Ribbon of the Global Genes project. The Blue Denim Ribbon is a symbol of hope for people fighting rare diseases and it is worn on Global Rare Diseases Day, the last day of February. Various events aimed at generating rare diseases awareness and support are also organized globally through the month of March.

In March 2017, the Blue Ribbon Rare Disease Symposium provided clinical and research updates by experts from leading research organizations, institutes, industry and state agencies. The speakers and panellists included internationally reputed experts and thought leaders from clinical medicine, medical research, medical technology, health informatics, ethics and law. They presented expert knowledge on carrier and new born screening, state of the art diagnostics, treatments and care of rare diseases. Rare disease policy and ethical issues was also discussed.

Blue Ribbon Rare Disease Symposium 2018 also brings various rare disease experts such as clinicians, researchers, patients and families as well as policy makers on a common platform. The symposium will disseminate new knowledge and provide valuable updates to stakeholders on various rare diseases including rare cancers. In keeping with Global Rare Disease Day theme of **"Research"** the symposium focuses on providing current research and updates on various rare diseases.

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Schedule

10:00 AM: Inaugural address
Dr. Vijay Chandru, Hon. Director, CHET, IIACD

10:10– 10:20 AM: Inauguration of the symposium
Shri. Ajay Seth, Principal Secretary, Ministry of Health & Family Welfare, GoK
Dr. S. Banakar, Deputy Director and Chief Nodal Officer, State Blood Cell

10:20–10:40 AM: Unveiling of **"OPFORD"** digital platform for rare diseases
Keynote on orphan drugs policy and need for fast-track clinical trials
Dr. Kiran Mazumdar-Shaw, CMD, Biocon

10:40 –11:10 AM: TEA BREAK

Session I: Treatment, Cure and Research for Rare Diseases
Moderator: **Dr. Vijay Chandru**

11:10 – 11:30 AM: Treatment and curatives for Primary Immune Deficiencies
Dr. Sagar Bhattad, ASTER CMI hospital

11:30 – 11:50 AM: Bone Marrow Transplant options for Primary Immune Deficiencies
Dr. Stalin, ASTER CMI hospital

11:50 – 12:20 PM: Gene therapeutic possibilities for rare pediatric cancers
Dr. Arka Subra Ghosh, Narayana Nethralaya

12:20 – 12:40 PM: Genetics of metabolic disorders - MPS
Dr.Sudha Srinivasan, Centre for Human Genetics

12:40 – 01:00 PM: Journey of DART: From lab to clinical trials
Berty Ashley, Dystrophy Annihilation Research Trust (DART)

01:00 – 01:15 PM: Audience questions

01:15 – 02:00 PM: LUNCH

Session II: Therapeutic Futures for Rare Diseases
Moderator: **Dr. Namitha A Kumar**

02:00 – 02:20 PM: Future therapies for rare diseases
Dr. Meenakshi Bhat, Clinical Genetics Faculty, Centre for Human Genetics

02:20 – 02:40 PM: Therapeutics for rare cancers (TBA)
Dr. Prasad Narayanan, Cytecare hospitals

02:40 – 03:00 PM: Gene therapies and genetic counselling for rare eye diseases
Dr. Anupreeta Ghosh, Senior Scientist – GROW Labs

03:00 – 03:15 PM: Audience questions

03:15 – 03:30 PM: TEA

Session III: Policy Initiatives for Rare Diseases
Moderator: **TBD**

03:30 – 03:50 PM: Karnataka's policy initiatives for rare diseases
Dr. Jagadish Mittur, KBITS, GoK

03:50 – 04:10 PM: GNE Myopathy – perspectives on past and future
Shubhraa Sinha, World without GNE Myopathy

04:10 – 04:30 PM: Need for alternative fast track clinical trial models
Ravdeep Anand, Dystrophy Annihilation Research Trust

04:30 – 04:50 PM: Rare diseases in Rights of People with Disability Bill
Dr. Namitha A Kumar, CHET

04:50 – 05:10 PM: Audience questions

05:10 – 05:30 PM: Closing note and vote of thanks
Prof. Uma V Chandru, Director, IIACD

Registration: Free

For registering and further information please contact:

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