Concept Note

Blue Ribbon Rare Diseases Symposium 2018

Centre for Health Ecologies and Technology (CHET)
International Institute of Art, Culture and Democracy (IIACD)

Date: March 14, 2018 (10 am - 6 pm)
Venue: Auditorium, National Gallery of Modern Art (NGMA) Bengaluru

The *Centre for Health Ecologies and Technology* (CHET) at *the International Institute of Art, Culture and Democracy* (IIACD), Bangalore presents the Blue Ribbon Rare Diseases Symposium 2018 on March 14, 2018 (10 am - 6 pm). Jointly organized under our Medical Humanities and Bioethics Initiative (MHBI) and Autism and Rare Disease Awareness (ARDA) outreach programme since 2016, the Blue Ribbon Rare Diseases Symposium and other Blue Ribbon events have been inspired by the Blue Denim Ribbon of the Global Genes project. A symbol of hope for people fighting rare diseases, the Blue Denim Ribbon is worn on the last day of February which is World Rare Diseases Day. In India and other countries, various events aimed at "raising awareness about rare diseases and the daily impact living with a rare disease has on patients and families" are also organized by rare disease advocates in the month of February and March each year.

Blue Ribbon Rare Disease Symposium 2018 brings various rare disease experts including clinicians, researchers, patients, families, other caregivers, advocates, policy makers and industry experts on a common platform. Following the **World Rare Disease Day** theme of **"Research,"** this symposium focussed on rare diseases and rare cancers will disseminate new knowledge on research, treatment and policy. Speakers and panellists included internationally reputed experts and thought leaders from clinical medicine, medical research, medical technology, health informatics, ethics and law. Our Chief Guest this year is Dr. Kiran Mazumdar-Shaw, CMD BIOCON Ltd. and Chairperson of ABLE & VGBT, who has been active in initiating the Rare Disease Policy for Karnataka and the regulatory pathways for Orphan drug development in India.

For Registration and further information please contact:

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Blue Ribbon Rare Diseases Symposium 2018 Schedule

March 14, 2018 (10 am - 6 pm)

10:00 AM: *Introduction*
Dr. Vijay Chandru, Hon. Director, CHET, IIACD

10:10 - 10:25: *Inauguration of Symposium &* ***OPFORD*** rare diseases digital platform launch
Chief Guest: Dr. Kiran Mazumdar-Shaw, CMD, Biocon
Guest of Honour: Dr. S. Banakar, Dy Director & Chief Nodal Officer, State Blood Cell, GoK

10:25 - 10:40: *Orphan drugs policy and need for fast-track clinical trials*
Dr. Kiran Mazumdar-Shaw, CMD, Biocon

Session 1: Rare Disease Non-discrimination, Cure and Care
Moderator: Dr. Vijay Chandru, Hon. Director, CHET

10:40 - 10:55: *Emerging therapies in rare genetic disorders*
Dr. Meenakshi Bhat, Clinical Genetics Faculty, Centre for Human Genetics

10.55 - 11.10: *Cell based therapies for rare diseases*
Dr. Sharat Damodar, Chief of Hematology, Mazumdar Shaw Cancer Centre

11:10 - 11:25: *Genomic Information Non-discrimination*
Rahul Matthan, Senior Partner, Trilegal

11:25 - 11:45: TEA BREAK

11:45 - 12:00: *Treatment and curatives for Primary Immune Deficiencies*
Dr. Sagar Bhattad, ASTER CMI hospital
12:00 - 12:15: *Bone Marrow Transplant options for Primary Immune Deficiencies*
Dr. Stalin Ramprakash, ASTER CMI Hospital
12:15 - 12:30: *Genetics of metabolic disorders - MPS*
Dr. Sudha Srinivasan, Centre for Human Genetics
12:30 - 12:45: *Gene therapeutic possibilities for rare pediatric cancers*
Dr. Arka Subra Ghosh, Narayana Nethralaya
12:45 - 1:00: Open Session

1:00 - 2:00: LUNCH

Session II: Therapeutic Futures for Rare Diseases
Moderator: Dr. Namitha A Kumar, Research Director, CHET

2:00 - 2:15: *Therapeutics for rare cancers (TBA)*
Dr. Prasad Narayanan, Cytecare hospitals
2:15 - 2:30: *Gene therapies and genetic counselling for rare eye diseases*
Dr. Anupreeta Ghosh, Senior Scientist – GROW Labs
2:30 - 2:45: *Journey of DART: From lab to clinical trials*
Berty Ashley, Dystrophy Annihilation Research Trust (DART)
2:45 - 3:00: TBA

3:00 - 3:15: *Towards affordable gene therapies for Hemophilia and Thalassemia*
Dr. Alok Srivastava, Professor of Medicine, Department of Haematology
Head, Centre for Stem Cell Research, Christian Medical College

3.15 - 3:30: Audience questions

3:30 - 4:00: TEA

Session III: Rare Disease Policy and Governance
Moderator: *Nitin Pai, Founder-Director, Takshashila Institute*

4:00 - 4:15: *Karnataka's policy initiatives for rare diseases*
Dr. Jagadish Mittur, KBITS, GoK
4:15 - 4:30: *GNE Myopathy - perspectives on past and future*
Shubhraa Sinha, World without GNE Myopathy
4:30 - 4:45: *Need for alternative fast track clinical trial models*
Ravdeep Anand, Founder-Director, Dystrophy Annihilation Research Trust
4:45 - 5:00: *Rare diseases in the "Rights of People with Disability Bill"*
Dr. Namitha A Kumar, Research Director, CHET
5:00 - 5:30: *Open session*

5:30 - 5:45 PM: *Closing note and vote of thanks*
Prof. Uma V Chandru, Director, IIACD