

Concept Note and Schedule

BLUE RIBBON ART CAMP AND FILM FESTIVAL 2018

National Gallery of Modern Art Bengaluru

(Ministry of Culture, Government of India)

49, "Manikyavelu Mansion"

Palace Road, Bengaluru - 560052

Tel no: 080 2234 2338

in collaboration with

International Institute of Art, Culture and Democracy

BLUE RIBBON ART CAMP 2018

Date: Saturday, 17 March 2018 (10 am - 1 pm)

Visual arts like drawing and painting can be healing tools through which people can convey and communicate their thoughts, emotions and experiences. For adults and children with rare diseases, art can serve as a therapeutic medium for expressing their struggles and frustrations while dealing with their diseases and also help with their emotional and psychological healing.

Blue Ribbon Art Camp 2018 has been designed as a patient-centric creative and therapeutic activity for 20 children and young adults (aged 10-20) with rare diseases to explore art and express their lived experiences of their disease. Art Camp facilitator Smt. Ranjana Ramchander is a talented painter whose paintings are with collectors across India, in Dubai, Singapore and other countries. She is also the co-founder of Hemophilia Society, Bangalore Chapter. She will be supported by the Autism and Rare Disease Awareness Generation (ARDA) programme artists and designers at IIACD who have organized workshops for children and young adults and are sensitized to the spectrum of differences in the human body and invisible disabilities faced by rare disease patients.

Pre-Registration Required: Contact: namitha@iiacd.org; 8722719519

Pre-registration Deadline: 15 March, 2017 (5 pm)

Pre- Registration Criteria:

- The Blue Ribbon Art Camp 2018 has been designed for children and young adults between 10- 20 years with rare diseases like metabolic, blood and neurogenetic disorders. Inclusive to children and young adults with special needs
- Limited to 20 participants on first cum first served basis

- Participants with special needs must be accompanied by one parent/guardian
- Any special devices, special food, drinks or medication needed by patients must be carried by patient/parent/guardian.
- Venue is wheelchair accessible.
- Art materials will be provided free of cost
- Lunch will be provided to registered participants and only one accompanying person

BLUE RIBBON RARE DISEASE FILMS SCHEDULE

2: 00 - 2:10: *Introduction*, Dr Satyabhama Badhreenath, Director, NGMA, Bengaluru

2:10 - 2:20: *Curatorial Note*, Dr. Namitha A Kumar, Research Director, Centre for Health Ecologies and Technology, IIACD, Bengaluru

2:20 - 3:25: ***Twitch*** (Huntington's disorder) Director: Kristen Powers, 43 mins

3:25 - 3:30: ***Nathan's Story*** (Tay Sach's Disease in Ireland) Producer: Einstein Health, 5 min

3:30 - 3:40: ***In Memory of Gavin*** (Niemann Pick Type C Disorder)

Director: Gavin's family, 10 mins

3:40 - 3:45: ***Beautiful Syndrome: Connor's Story*** (Nicoladies-Baraitser Syndrome)

Director: Megan Angel, 12 mins

3:45 - 4:05: ***Gangliosidosis: The Monster in the House*** (Gangliosidosis)

Director: Kat Morkay, 25 mins

4:05 - 4:15: ***Caleb's Story - Rare Rett Syndrome boy*** (Rett Syndrome)

Director: Caleb's family, 7 mins

4:15 - 4:25: ***Our Daughter's Rare Diagnosis - Angelman Syndrome***

Director: Hisko family, 8 mins

4:25 - 4:40: Tea Break

4:40 - 5:25: ***Kids with Tourette's: In Their Own Words*** (Tourette's syndrome)

Produced by Real Stories, 45 mins

5:25 - 5:30: ***Paper Planes: Dreams of a Million Children*** (Osteogenesis Imperfecta)

Director: Hema Ramesh, One Step at a Time, Duration: 5 mins

5:30 - 6:00: ***Living with Spina Bifida: Shakti Krishnan*** (Spina Bifida)

Produced by Attitude films, Duration: 30 mins

6:00 - 6:45: ***Hayley, the world's oldest teenager*** (Progeria)

Produced by Real Stories, Duration – 45 mins

6:45 - 6:55: *Audience interaction*, Moderator: Chaitra Chandapillai, IIACD

6:55 - 7:00: *Vote of thanks*, Ambassador V. Latha Reddy, Trustee, IIACD