

CO-HOSTED BY NITI Aayog SUPPORTED BY EMBASSY OF JAPAN INITIATIVE COLLABORATORS NATIONAL HEALTH MISSION GOVERNMENT OF KARNATAKA GOVERNMENT OF INDIA CO-POWERED BY Takeda INITIATIVE BY PPHF

GLOBAL RARE DISEASE CONFERENCE

BLUEPRINT FOR RARE DISEASES

28 | 02 | 2021
5:45 PM - 9:30 PM IST

RESEARCH PARTNER GRID Council TECHNICAL PARTNER aequitas STRATEGIC PARTNERS ORD RARE DISEASES INDIA FOUNDATION LSDSS Cure SMA India Roche MEDIA PARTNER Healthworld.com KNOWLEDGE PARTNER

CONFERENCE SCHEDULE

5:45PM – 6:00 PM	Social Networking, Photo booth, Exhibition and Gallery Walk (Digital)	
Session 1 - Inauguration		
Context Setting		
6:00PM - 6:05PM	Opening remarks by Dr. Archisman Mohapatra, Executive Director, GRID Council	
6:05PM – 6:10PM	Setting the Context: A video on “What drives our commitment for Rare Diseases – Let’s come together as one Universe”	
Opening Ceremony		
6:10PM-6:15PM	Welcome address	Dr. Laxmikant Palo – CEO – PPHF
6:15PM-6:20PM	Oath taking ceremony – video presentation by Cure SMA Foundation of India	Inviting all the participants for taking Oath along with our SMARt Warriors – Rare Diseases Patient
6:20PM-6:30PM	Keynote address by the Guest of Honor (national)	Dr. Rakesh Sarwal, Additional Secretary, Niti Aayog
6:30PM-6:40PM	Keynote address by the Guest of Honor (national)	Shri. Rajender Kumar, Director, Prime Minister’s Office, Government of India
6:40PM-6:50PM	Keynote address by the Guest of Honor (national)	Prof. Rajendra Pratap Gupta, Chair-Dynamic Coalition on ‘Internet & Jobs’, Internet Governance Forum United Nations, Mumbai Metropolitan Region
6:50PM-7:00PM	Keynote address by the Guest of Honor (International)	Dr. Mahender Nayak, Area Senior Vice-President, ICMEA, Takeda
7:00PM- 7.15PM	Scribble Wall Break - Requesting participants to take a 15 mins break to move to the scribble wall for posting One Idea that can impact Rare Diseases Policy and Program in India	

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Session 2: Best Practices on Rare Diseases

	Track 1	Track 2
7:15PM-8:00PM	<p>Policies and partnerships (Dr. Archisman Mohapatra will be welcoming the speakers followed by the moderator)</p> <p>Moderator – Dr. K. Madan Gopal, Senior Consultant, Niti Aayog</p> <p>Speaker 1: Taking Action for Rare Diseases- Together to Drive Impact: Ms. Susanne Weissbaecker, Head Access to Medicine, GEM, Takeda</p> <p>Speaker 2: Rare Disease- Collective Action through Global Partnerships: Ms. Durhane Wong-Reiger, President & CEO, CORD</p> <p>Speaker 3: Personal Genomes to Precision Medicine- Implications for Rare Genetic Diseases in India: Dr. Sridhar Sivasubbu, Scientist, CSIR Institute of Genomics and Integrative Biology, Co-founder of GUARDIAN, New Delhi</p>	<p>Engagement of PAGs to influence policies and programs (Mr. Saad Ali Khan will be welcoming the speakers followed by the moderator)</p> <p>Moderator- Dr. Bobby John, Managing Director, Aequitas Consulting Pvt. Ltd.</p> <p>Speaker 1: Turning rare disease grief into action: Mr. Blaine Penny, Treasurer & Director, CORD</p> <p>Speaker 2: Empowering Patients, supporting Non-profit Organisations: How NORD connects Patients, Researchers & Industry: Ms. Debbie Drell, Director of Membership, NORD</p> <p>Speaker 3: Advocacy journey in India: Mr. Prasanna Shirol, Co-Founder & Executive Director, ORDI</p> <p>Speaker 4: Every life is precious: Ms. Alpana Sharma, Co-founder and Director Patient Advocacy – Pharma, Cure SMA Foundation of India</p>
8:00PM-8:05PM	Break	

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Session 3: Setting priorities and the urgency on Rare Disease		
	Track 3	Track 4
8:05PM-8:55PM	<p>Mobilizing resources & Sustainable funding mechanism for treatment to the patients, research, and RD program (Dr. Archisman Mohapatra will be welcoming the speakers followed by the moderator)</p> <p>Moderator- Dr. Vijayshree Yellappa, Fellow, Niti Aayog, Government of India</p> <p>Speaker 1: Sustainable funding mechanisms to support access to new treatments, increased research, and rare disease programs: Ms. Yukti Bhargava, Global Senior Access Strategy leader, Rare Diseases, Roche</p> <p>Speaker 2: Mr. Abbey Ogunwale, PhD, CEO & Principal, Defined Impact Group</p>	<p>Better Infrastructure and improved capacity for early diagnosis, monitoring, education, and research (Mr. Saad Ali Khan will be welcoming the speakers followed by the moderator)</p> <p>Moderators- Dr. Reeta Rasaily, Senior Scientist, Head Division of RBMCH & N, ICMR & Dr. Madhulika Kabra, Professor, Division of Genetics, Dept. of Paediatrics, AIIMS</p> <p>Speaker 1: Research in Rare Diseases: ICMR Initiatives: Dr. Reeta Rasaily, Senior Scientist, Head Division of RBMCH & N, ICMR</p> <p>Speaker 2: Early Diagnosis of Rare Diseases in India - Strategies & Solutions: Dr. Neerja Gupta, Associate Professor, Division of Genetics, Dept. of Pediatrics, AIIMS</p> <p>Speaker 3: Why US-India collaborations are crucial to accelerating therapies for rare diseases? Mr. Harsha Rajasimha, Founder & Chairman, IndoUSrare</p>

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8:55 PM-9:10 PM	Regional Rare Disease Recommendations from India	<p>Speaker 1: Dr. Amandeep Kaur Kang, MD, NHM, UT of Chandigarh</p> <p>Speaker 2: Dr. Tanushree Mondal, Deputy Director of Medical Education, Govt. of West Bengal</p> <p>Speaker 3: Dr Arundhati Chandrashekhar, IAS, Mission Director, NHM, Dept of Health & Family, Govt of Karnataka, Karnataka</p>
9:10PM-9:15PM	Initiative's journey & release of Call to Action-digital booklet	Dr. Madhulika Kabra, Professor, Division of Genetics, Dept. of Paediatrics, AIIMS
9:15PM-9:25PM	Closing remarks	Dr. Laxmikant Palo, CEO, PPHF & Mr. Koki Sato, General Manager, India, Takeda
9:25PM-9:30PM	Balloons releasing ceremony marking the new Beginning	A small presentation by LSDSS

***Please don't forget to download your e-certificates of participation**

Side Events: Media interactions of key stakeholders, photo booth, Social Networking hall, Gallery Walk