



2ND BRAZILIAN FORUM OF
HTA FOR RARE DISEASES

2nd Brazilian Forum of Health Technology Assessment for Rare Diseases

Held by: Instituto Unidos pela Vida

Venue: Blue Tree Premium Morumbi (Sala Topázio I e II) - São Paulo/SP - With live transmission and simultaneous translation into English and Spanish



Unidos pela Vida
Instituto Brasileiro de Atenção à Fibrose Cística

PANEL	BEING	PROGRAMME		SPEAKER
WEDNESDAY - NOVEMBER 22, 2023				
Opening	09:00	Opening	Welcome / Opening / UPV Anniversary / Forum Presentation	Msc Verônica Stasiak and Dr. Marise Basso Amaral
PANEL 1	09:20	<i>New Brazilian horizons for rare diseases</i>	Health Economic Industrial Complex (CEIS) and rare diseases: challenges and possibilities	Dr. Carlos Gadelha (TBC)
			National initiatives for innovation in rare diseases	Dr. Marco Aurelio Krieger (TBC)
			Debate	Natalia Cuminale
Coffee Break	10:30	COFFEE BREAK		
PANEL 2	10:45	<i>Social Engagement and the impact of narratives in the HTA decision-making process</i>	What patients have to say: real-life testimonials of public consultations and their impact on decision-making	Dr. Marise Basso Amaral
			Case Study: How have reports been analyzed and considered in HTA?	MSc Verônica Stasiak Bednarczuk de Oliveira
			Debate	Natalia Cuminale
Lunch Break	12:10	LUNCH BREAK		
PAINEL 3	14:00	<i>The ways to generate real-world evidence for HTA</i>	The importance of data in the HTA process: the case of the Brazilian cystic fibrosis registry	Dr. Luiz Vicente Ribeiro
			Producing real-life evidence in Brazil for HTA	Dr. Rodrigo Athanazio
			The pathways to generating real-world evidence	Dr. Ramón Pereira
			Debate	Natalia Cuminale
Coffee Break	15:15	COFFEE BREAK		
PAINEL 4	15:30	<i>Access and sustainability challenges in SUS</i>	Pricing policies for medicines in Brazil: a look at rare diseases	Dra. Marcela Amaral Pontes
			Cost-effectiveness thresholds for rare diseases: how to ensure equity?	Dr. Luciene Bonan (TBC)
			Debate	Natalia Cuminale
Closing Lecture	16:40	Telehealth: Reality and Future in Medicine & the inspiring story of the Laura Fressato Institute, the algorithm that seeks to impact 1 billion lives		Jacson Fressatto
		Debate with Jacson		Natalia Cuminale
Wrap Up	17:15	Wrap Up		MSc Verônica Stasiak Bednarczuk de Oliveira

**The schedule can be changed without prior notice during the entire execution of the project, due to internal or external conditions, whether of a strategic, technical-operational, political, sanitary or environmental nature.*



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THURSDAY - NOVEMBER 23, 2023				
Opening	09:00	Opening		MSc Verônica Stasiak Bednarczuk de Oliveira
PANEL 5	09:15	<i>Social Control</i>	High-cost treatments for rare diseases in the SUS and supplementary health and the challenges of overall access	MSc Marina Magalhães
			Legislative initiatives to improve the care of patients with rare diseases	Senador Fabiano Contarato (TBC)
			Debate	Natalia Cuminale
Coffee Break	10:25	COFFEE BREAK		
PANEL 6	10:40	<i>Transversal Themes</i>	How to ensure access beyond drugs in rare diseases: the case of specialized nutrition	Dr. Paulo Pedro Dal Bello (TBC)
			Real-life study: decision-making criteria in HTA for rare and respiratory diseases	Dra. Fabiana Gatti de Menezes
			Debate	Natalia Cuminale
Lunch Break	12:10	LUNCH BREAK		
PANEL 7	14:00	<i>Social Engagement in SUS</i>	Spaces for social engagement in HTA in SUS and the importance of occupying them	Priscila Torres
			What are the main decision factors that lead to incorporations in international agencies	MSc Iara Bernz
			Debate	Natalia Cuminale
Coffee Break	15:10	COFFEE BREAK		
PANEL 8	15:25	<i>Health Literacy for HTA qualification</i>	Health education as a way to qualify the HTA process	Dr. Cristina Guimarães
			Qualifica & Conexão SUS: Launch of the Social Participation Mapping Project in Brazil and capacity building for patient associations	MSc Verônica Stasiak Bednarczuk de Oliveira
			Debate	Natalia Cuminale
Wrap Up	16:35	Wrap Up		MSc Verônica Stasiak e Dra. Marise Basso Amaral