

ON INHERITED NEUROTRANSMITTER RARE DISEASES

ABOUT THE EVENT

FORUM

This event follows the Belgrade Conference of last year funded by the European Joint Program on Rare Diseases (EJP RD COFUND-EJP N° 825575). We are aware that common difficulties regarding the context of rare diseases are:

- lack of proficient/accessible communication
- need for simplified language between healthcare professionals, scientists and stakeholders
- absence/poor best practices
- need for a more efficient networking

A group of young clinicians, scientists, and patient advocacy representatives will meet in Verona (Italy) and join their forces in an interdisciplinary exchange, to promote an example of efficient and accessible communication and a strengthened networking.

The discussion will start from specialized knowledge with the aim to improve accessibility to science. During the whole day, there will be the possibility to join the meeting remotely and take active part to discussion in order to allow a continuous dialogue between the whole community. The outputs of this forum will provide a best practice in bringing knowledge form specialized professionals to all stakeholders.

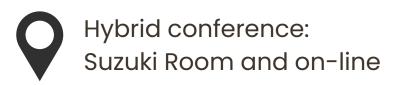
We are very pleased to invite you to contribute to this conference by your online participation by clicking at the following link:

https://univr.zoom.us/s/91388820620.

No registration to event is required, but participants are kindly ask to communicate their attendance to **youngscientisteventverona@gmail.com**.

Sponsored by: PTC Therapeutics, Italy







PROGRAM Saturday 16 September 2023

09:00 - 09:15	Welcome note & opening / Virtual Platform networking	Mariarita Bertoldi Ivana Badnjarevic Claudio Cinquemani
09:15-10:15	Impulse speeches by participants (5 minutes each)	All (in-person and online participants)
10:15 - 10:30	Break	
10:30 – 11:00	Inherited disorder of neurotransmitters: a two-voices introduction	Giada Rossignoli Heiko Brennenstuhl
11:00 – 11:30	Retelling the story (5 minutes each): assessing the language/concepts used by the colleague	Giada Rossignoli Heiko Brennenstuhl
11:30 – 12:00	AADC deficiency: the point of views of a young scientist and a young clinician	Giovanni Bisello Yilmaz Yildaz
12:00 – 12:30	Retelling the story (5 minutes each): assessing the language/concepts used by the colleague	Giovanni Bisello Yilmaz Yildaz
12:30 - 13:00	Q&A, Panel discussion	All (in-person and online participants)
13:00 - 14:00	Break	
14:00 - 14:30	TH and SSADH deficiencies: the point of views of a young scientist and a young clinician	Kristel Klaassen Jan Kulhánek
14:30 - 15:00	Retelling the story (5 minutes each): assessing the language/concepts used by the colleague	Kristel Klaassen Jan Kulhánek
15:00 – 15:30	Q&A, Panel discussion	All (in-person and online participants)
15:30 – 15:45	Break	
15:45 - 16:15	European Reference Network on Hereditary Metabolic Disorders - MetabERN: opportunities for young scientists	Epaminondas La Bella
16:15 - 17:30	(How) Can we best communicate amongst rare disease stakeholders?	Claudio Cinquemani and all (in-person and online participants)
17:30-18:00	Panel discussion and closing remarks	(in-person and online participants)





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