Thought Leader Session: The Global Commission to End the Diagnostic Odyssey for Children with a Rare Disease

EVENT DATE & TIME | MAY 7, 2024 AT 8:00AM EST (14.00 CET)

EVENT OVERVIEW | Since 2018, the Global Commission to End the Diagnostic Odyssey for Children with a Rare Disease – a multidisciplinary group of rare disease advocates, researchers, physicians, and technologists – has been working towards its vision of a clear path to a timely, accurate rare disease diagnosis for all children. We are excited to share the Global Commission's renewed efforts and progress to date.

In this session, Global Commission members and co-chairs will share their newly developed global framework to help guide countries in strengthening their diagnostic efforts. This framework will include a resource compendium with case studies of successful initiatives that have made strides to shorten the time to rare disease diagnosis, highlighting learnings for other countries to draw on. The Global Commission is excited to release these materials at the webinar and will call for others in the rare disease community to submit successful examples that we can include in this framework.

EVENT GOALS |

- Re-introduce the Global Commission and its commitment to end the diagnostic odyssey for children living with a rare disease on a global stage
- Present the framework and a preview of the resource compendium
- Provide a platform for Global Commission members to share success stories, challenges and overall learnings on how to improve global and regional environments for rare disease diagnosis

LEARNING OBJECTIVES|

After this session, participants will be able to:

- Summarize the value of the Global Commission and its commitment to end the diagnostic odyssey for children living with a rare disease
- Share examples of successful initiatives working to reduce the time to rare disease diagnosis
- Explain remaining gaps in the rare disease community and how the Global Commission's work factors in

AGENDA & SPEAKERS |

Welcome & Introduction to the Global Commission	**Yann Le Cam**, *EURORDIS*, Global Commission Co-Chair **Neil Inhaber**, *Takeda*, Global Commission Co-Chair
Panel Discussion: Showcase successes in accelerating diagnosis	**Moderator:** **Mike Porath**, *The Mighty* **Panelists:** **Gareth Baynam**, *Rare Care Centre, Perth Children's Hospital* **Roberto Giugliani,** *Casa dos Raros, Dasa, HCPA, UFRGS* **Alexandra Heumber**, *Rare Disease International*
Co-chair: Closing Remarks and Call to Action	**Alaa Hamed,** *Sanofi*, Global Commission Co-Chair