

2025 馬偕兒童醫院 罕見疾病國際論壇

· 時間：2025/04/12 (六) 09:00~17:00			
· 地點：馬偕紀念醫院平安樓 15 樓階梯講堂 (台北市中山北路 2 段 92 號)			
· 主辦單位：馬偕紀念醫院、馬偕兒童醫院、臺灣兒科醫學會			
Time	Agenda		
8:30-9:00	Registration 報到		
9:00-9:10 (10 mins)	Opening remarks	陳銘仁院長 (馬偕兒童醫院)	
Time	Title of the Talks	Speakers	Moderators
9:10-9:50 (40 mins)	Unmet needs of current treatment in mucopolysaccharidoses: Addressing CNS and bone involvement	Prof. Sung Yoon Cho (趙晟允) (Samsung Medical Center, Sungkyunkwan University, Seoul, Republic of Korea)	林翔宇主任 (馬偕兒童醫院)
9:50-10:30 (40 mins)	One and only Taiwan newborn screening for mucopolysaccharidoses updates worldwide and a well-established screening test for alpha-mannosidosis	莊志光研究員 (馬偕紀念醫院)	
10:30-10:50 (20 mins)	Break		
10:50-11:30 (40 mins)	Long-term benefit of oral therapy in managing spinal muscular atrophy	Prof. Furene Wang (National University Hospital, Singapore)	陳錫洲主任 (三軍總醫院)
11:30-12:10 (40 mins)	The change of spinal muscular atrophy therapy after newborn screening (新生兒篩檢後，脊髓性肌肉萎縮症治療的改變與現況)	許庭榕醫師 (臺北榮民總醫院)	
12:10-13:30 (50 mins)	[Lunch Symposium] New trends in diagnosis and treatment of acid sphingomyelinase deficiency (ASMD) (酸性鞘磷脂酶缺乏症之診斷與治療)	周言穎醫師 (國立成功大學醫學院附設醫院)	郭雲鼎主任 (部立雙和醫院)

13:30-14:10 (40 mins)	Multi-disciplinary approach in diagnosis & management of Fabry disease - Japan experience	Prof. Kazuya Tsuboi (坪井一哉) (Nagoya Central Hospital, Nagoya, Japan)	洪崇烈主任 (馬偕紀念醫院)
14:10-14:50 (40 mins)	Cardiac care in Fabry disease (法布瑞氏症之心臟醫療照護)	宋國慈醫師 (馬偕紀念醫院)	
14:50-15:10 (20 mins)	Break		
15:10-15:50 (40 mins)	Lessons learned from pediatric clinical exome (從兒科臨床全外顯子定序汲取的教訓與經驗)	李妮鍾教授 (臺大醫院)	林炫沛教授 (馬偕兒童醫院)
15:50-16:30 (40 mins)	Decoding the future: Next-generation genetic diagnostics and the clinical revolution in personalized medicine (解碼未來：新一代基因診斷技術與個人化醫療的臨床革命)	李忠霖醫師 (馬偕兒童醫院)	
16:30-16:40	Closing remarks	林炫沛教授 (馬偕兒童醫院)	

報名 QR Code

