

## Rare Disease Symposium 2024 罕病研討會 2024

### List of Moderators (in order of appearance) 主持人名單 (按出場序):

- ✧ Prof. Danny CHAN, Senior Advisor (Policy and Governance), School of Biomedical Sciences, The University of Hong Kong  
香港大學生物醫學學院資深顧問 (政策及管治) 陳振勝教授
- ✧ Dr. FUNG Cheuk-wing, Consultant (Metabolic Medicine), Department of Paediatrics and Adolescent Medicine, Hong Kong Children's Hospital  
香港兒童醫院兒童及青少年科顧問醫生 (先天性新陳代謝科) 馮卓穎醫生
- ✧ Prof. Janus WONG, Clinical Assistant Professor, Department of Orthopaedic & Traumatology, School of Clinical Medicine, The University of Hong Kong  
香港大學矯形及創傷外科學系臨床助理教授 黃兆謙教授
- ✧ Mr. LI Linkang, Executive Director, China Alliance for Rare Diseases  
中國罕見病聯盟執行理事長 李林康先生

### List of Speakers (in order of appearance) 講者名單 (按出場序):

- ✧ Prof. LAU Chak-sing, Dean of Medicine, LKS Faculty of Medicine, The University of Hong Kong  
香港大學李嘉誠醫學院院長 劉澤星教授
- ✧ Mr. LI Linkang, Executive Director, China Alliance for Rare Diseases  
中國罕見病聯盟執行理事長 李林康先生
- ✧ Mr. TSANG Kin-ping, Chairman, Rare Disease Hong Kong  
香港罕見疾病聯盟會長 曾建平先生
- ✧ Prof. ZHANG Shuyang, President, Peking Union Medical College Hospital  
北京協和醫院院長張抒揚教授
- ✧ Dr. Michael WONG, Director (Quality & Safety), Hospital Authority, Hong Kong  
香港醫院管理局質素及安全總監 黃立己醫生
- ✧ Prof. Kenneth CHEUNG, Hospital Chief Executive, The University of Hong Kong-Shenzhen Hospital  
香港大學深圳醫院院長 張文智教授
- ✧ Ms. Alexandra HEUMBER-PERRY, Chief Executive Officer, Rare Diseases International (國際罕見疾病聯盟行政總裁)
- ✧ Dr. Brian CHUNG, Chief Medical and Scientific Officer, Hong Kong Genome Institute  
香港基因組中心首席醫務及科學總監 鍾侃言醫生
- ✧ Prof. Laurence LEGEAI-MALLET, Director of Research, French National Institute for Health and Medical Research, Imagine Institute, Université de Paris Cité (法國國家健康與醫學研究所研究主任)
- ✧ Prof. SHEN Min, Deputy Executive Director, Department of Rare Diseases, Peking Union Medical College Hospital  
北京協和醫院罕見病醫學科常務副主任 (主持工作) 沈敏教授

- ◇ Prof. Tiong Yang TAN, Clinical Geneticist, Victorian Clinical Genetics Services, Murdoch Children's Research Institute, Australia (澳洲默多克兒童研究所維多利亞臨床遺傳學服務中心臨床遺傳學家)
- ◇ Prof. Nick Bishop, Chair in Paediatric Bone Disease, Clinical Medicine, School of Medicine and Population Health, University of Sheffield, UK (英國雪菲爾大學醫學與人口健康學院臨床醫學小兒骨病主任)
- ◇ Prof. Tae-Joon CHO, Department of Orthopaedic Surgery, Seoul National University College of Medicine, Korea (韓國首爾國立大學醫學院骨科教授)
- ◇ Prof. Michael TO, Head, the Orthopedic Centre, The University of Hong Kong-Shenzhen Hospital 香港大學深圳醫院骨科醫學中心主任 杜啟峻教授
- ◇ Prof. DAI Yi, Deputy Director, Department of Neurology, Peking Union Medical College Hospital 北京協和醫院神經科副主任 戴毅教授
- ◇ Prof. Martin CHEUNG, Associate Professor, Associate Director (Research & Innovation), School of Biomedical Sciences, LKS Faculty of Medicine, The University of Hong Kong 香港大學醫學院生物醫學學院副教授及副主(研究及創新)張知恒教授
- ◇ Dr. LUK Ho-ming, Chief of Service, Department of Clinical Genetics, Hong Kong Children's Hospital 香港兒童醫院醫學遺傳科部門主管 陸浩明醫生
- ◇ Prof. Godfrey CHAN, Honorary Clinical Professor, Department of Paediatrics and Adolescent Medicine, School of Clinical Medicine, LKS Faculty of Medicine, The University of Hong Kong 香港大學李嘉誠醫學院兒童及青少年科學系榮譽臨床教授 陳志峰教授
- ◇ Prof. Sophelia CHAN, Clinical Associate Professor, Department of Paediatrics and Adolescent Medicine, School of Clinical Medicine, LKS Faculty of Medicine, The University of Hong Kong 香港大學李嘉誠醫學院兒童及青少年科學系臨床副教授 陳凱珊教授
- ◇ Dr. XIAO Haibing, Associate Consultant, Department of Neurology, The University of Hong Kong-Shenzhen Hospital 香港大學深圳醫院神經醫學中心副顧問醫生 尚海兵醫生
- ◇ Dr. Sheila WONG, Associate Consultant, Neurology team, Department of Paediatrics and Adolescent Medicine, Hong Kong Children's Hospital 香港兒童醫院兒童及青少年科腦神經科副顧問醫生 王雪娜醫生
- ◇ Dr SHENG Bun, Consultant, Department of Medicine and Geriatrics, Princess Margaret Hospital 瑪嘉烈醫院內科及老人科顧問醫生 盛斌醫生
- ◇ Prof. Janus WONG, Clinical Assistant Professor, Department of Orthopaedic & Traumatology, School of Clinical Medicine, The University of Hong Kong 香港大學矯形及創傷外科學系臨床助理教授 黃兆謙教授
- ◇ Prof. ZHANG Jianguo, Director, Department of Orthopedics, Peking Union Medical College Hospital 北京協和醫院骨科主任 仇建國教授
- ◇ Dr. Joanna Yuet-ling TUNG, Consultant (endocrinology), Department of Paediatrics and Adolescent Medicine, Hong Kong Children's Hospital 香港兒童醫院兒童及青少年科專科醫生(內分泌科)童月玲醫生

- ◇ Ms. Si-jia WU, CHN Dravet Syndrome Patient Support Group (Beijing)  
卓蔚寶貝支持小組 伍思嘉女士 (北京)
- ◇ Ms. Ai ZHENG, Chinese Organisation for Scleroderma (Sichuan)  
成都紫貝殼公益服務中心 鄭媛女士 (四川)
- ◇ Mr. Bo-cheng NING, FSHD-China Patient Advocacy and Support Organization (Heilongjiang)  
你並不孤單 FSHD 患者關愛組織 甯栢晟先生 (黑龍江)
- ◇ Ms. Fang WANG, Neurofibromatosis Shenzhen Care Center (Shenzhen)  
泡泡家園神經纖維瘤病關愛中心 王芳女士 (深圳)
- ◇ Ms. Dong-lei ZHONG, Twin Lotus Gorlin Syndrome Alliance (Hebei)  
並蒂蓮高林綜合征聯盟 仲冬蕾女士 (河北)
- ◇ Ms. Chris CHAN, Hong Kong Neuromyelitis Optica Association  
香港視神經脊髓炎協會 陳寶婷女士
- ◇ Ms. Rebecca YUEN, Tuberos Sclerosis Complex Association of Hong Kong  
香港結節性硬化症協會 阮佩玲女士
- ◇ Mr. Xiao-jin LIN, Prader-Willi Syndrome Care & Support Center (Zhejiang)  
小胖威利罕見病關愛中心 林曉靜先生 (浙江)
- ◇ Ms. Edwina LAI, Hand In Hand Association (Hong Kong)  
牽手同行協會 賴佩欣女士 (香港)
- ◇ Mr. Bing CHEN, Chinese Organization for Wilson Disease (Henan)  
銅娃娃罕見病關愛中心 晨冰先生 (河南)
- ◇ Mr. Davy WONG, The Hong Kong HAE Patient Group  
香港遺傳性血管水腫協會 黃耀文先生
- ◇ Mr. Man-lam LUI, Hong Kong Neuro-Muscular Disease Association  
香港肌健協會 呂文林先生
- ◇ Ms. Qing YAN, Tongxin Wilson Disease Information Service Center (Hubei)  
同馨肝豆資訊服務中心 嚴青女士 (湖北)
- ◇ Ms. Na-Zhen CHEN, Homy Familial Hypercholesterolemia Patient Organization (Shaanxi)  
紅米粒高膽固醇血症研究與服務中心 陳娜珍女士 (陝西)
- ◇ Mr. Jun WANG, Gaucher Disease Care Center (Shanxi)  
山西壹心公益發展中心 王軍先生 (山西)