Appendix

About Professor Edwin Chan Ho-yin

Professor Edwin Chan Ho-yin is Director and Professor in the School of Life Sciences, CUHK. He received undergraduate training in biochemistry from CUHK, doctoral training at The University of Cambridge (UK) and postdoctoral training at The University of Pennsylvania (US). Since 1999, Professor Chan has been investigating rare neurological and neuromuscular disorders. In 2014, he established an intercontinental research collaboration network on rare neuronal diseases, including Huntington's disease, amyotrophic lateral sclerosis, myotonic dystrophy and spinocerebellar ataxia. Professor Chan participates in community services, including as consultant to the Hong Kong Spinocerebellar Ataxia Association and Chairperson of its Scientific and Medical Advisory Committee. He is a Founding Member of the Hong Kong Young Academy of Sciences and served on its inaugural Executive Committee from 2019 to 2022. In 2023, he co-founded Rare Power Limited with chemical biologist Dr Maggie Leong, neuroscientist and geneticist Dr Aldrin Yim. The company aims to provide exceptional services to rare disease patients through the 3 "C"s: Care, Check and Cure. In 2024, Rare Power Limited was admitted to the Hong Kong Science and Technology Parks' IncuBio Programme.

About Professor Stephen Chen Zhefan

Professor Stephen Chen Zhefan is Assistant Professor in the School of Life Sciences, CUHK. After receiving a PhD degree, he was awarded a Postdoctoral Fellowship under the Clinical Neurosciences programme from CUHK and the University of Oxford's Nuffield Department of Clinical Neurosciences and Pembroke College. During his stay in Oxford, Professor Chen was under the supervision of Professor Kevin Talbot, Professor of Motor Neurone Biology and Head of the Nuffield Department of Clinical Neurosciences. Professor Chen offers editorial services to academic journals and international funding agencies. He also participates in the organisation of research symposiums, including as a member of the Organising Committee of the Hong Kong Inter-University Postgraduate Symposium in Life Sciences and a Discussion Leader at the Gordon Research Seminar for Molecular and Cellular Neurobiology.

About Mr Ken To

Mr Ken To lives in Hong Kong and has been the primary caretaker for his mother who was diagnosed with Huntington's Disease in 2003. He himself is at risk of carrying the mutation that causes the disease. Advocating for rare diseases is a significant aspect of his life. Throughout the years, Ken has been working closely with the local and international rare disease communities to raise awareness of the challenges rare disease families face. He witnessed the founding of the Chinese Huntington's Disease Network in 2011 and currently collaborates with the Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group as well as the Huntington's Disease Youth Organisation.

Ken highlighted caregiving challenges, such as fear, guilt, and powerlessness, as well as the anxiety of inheriting the mutation. These difficulties are universal but amplified in countries with low HD awareness. Ken plans to connect families and alleviate their burdens, and advocate for HD research and drug development.

About the Chinese Huntington's Disease Network

The Chinese HD Network, launched on 10 December 2011, aims to increase awareness of Huntington's disease (HD) in China and enhance care for families. A global advantage of the Network is enabling clinical research by finding more patients for therapeutic trials, crucial for advancing treatments.