

## **Appendix**

### **About Professor Edwin Chan Ho-yin**

Professor Edwin Chan Ho-yin is Professor in the School of Life Sciences at CUHK. He received undergraduate training in biochemistry from CUHK, doctoral training at The University of Cambridge and postdoctoral training at The University of Pennsylvania. Since 1999, Professor Chan has been investigating rare neurological and neuromuscular disorders. In 2014, he established an intercontinental research collaboration network for rare neuronal diseases, including amyotrophic lateral sclerosis, Huntington's disease, myotonic dystrophy and spinocerebellar ataxias. Professor Chan participates in community services, including as a consultant for the Hong Kong Spinocerebellar Ataxia Association and Chairperson of the Association's 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 his company Rare Power Limited, which aims to provide exceptional services to rare disease patients through the 3 "C"s: Care, Check and Cure.

### **About Dr Stephen Chen Zhefan**

Dr Stephen Chen Zhefan received his Ph.D. at the School of Life Sciences at CUHK. He was awarded a Postdoctoral Fellowship under the Clinical Neurosciences programme from CUHK and the University of Oxford (Nuffield Department of Clinical Neurosciences and Pembroke College). During his stay in Oxford, Dr Chen was under the supervision of Professor Kevin Talbot, the university's Professor of Motor Neurone Biology and Head of the Nuffield Department of Clinical Neurosciences. Dr Chen has received various presentation awards, including the Outstanding Platform Presentation Award from the Hong Kong Inter-University Postgraduate Symposium in Biochemical Sciences in 2016. He was an Organising Committee member of the Hong Kong Inter-University Postgraduate Symposium on Life Sciences in 2015, and served as Discussion Leader in the Gordon Research Seminar for Molecular and Cellular Neurobiology in 2018.

### **About the Hong Kong Neuro-Muscular Disease Association**

The Hong Kong Neuro-Muscular Disease Association (HKNMDA) is a self-help, non-profit charitable organisation for people suffering from neuro-muscular disease and their carers founded in 1998 under the Societies Ordinance and Inland Revenue Ordinance. It was incorporated as a limited company in 2012. The Association aims to improve the quality of life and promote efforts to create a favourable social environment for people with neuro-muscular disease and their families. It provides mutual support groups, psycho-educational programmes, volunteer visits, social and recreational activities, policy advocacy, information provision and public education activities.

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