

For Immediate Release

**Hong Kong to Host Landmark International Symposium on Genomic Medicine
*HKGI Partners with Global Leaders to Chart a Course for Healthcare Transformation***

(Hong Kong, 19 February 2025) Genomic medicine has been gaining global prominence for its vast potential to revolutionise healthcare services. In the case of rare conditions, genomic medicine has been particularly transformative, as approximately 80% of rare diseases are of genetic origin. Genomic medicine has the power to facilitate diagnosis and access to curative and life-changing treatments for people living with these rare conditions. Now, Hong Kong is set to partner with world-renowned authorities to drive exchanges dedicated to this burgeoning field, taking advantage of the city's unique strengths in medical research and development.

The **Hong Kong Genome Institute (HKGI)**, **Rare Diseases International (RDI)**, and **The Lancet Commission on Rare Diseases (LCRD)** will join forces for the first time to organise the ***International Genomic Medicine Symposium*** (Symposium) on **17 November 2025** (Monday) at the Hong Kong Science Park. This landmark event will convene distinguished experts, clinicians and scientists from over 20 countries and regions to foster knowledge exchanges in genomic medicine and rare diseases, representing a significant collaboration among leading institutions committed to accelerating the development of genomic medicine on a global scale and providing an unparalleled opportunity to improve outcomes for the 300 million persons living with a rare disease worldwide.

The Symposium, focusing on the latest advancements and trends in genomic medicine, features a robust lineup of local and international experts in genetics and genomics, including **Dr Chloe Wilson, Senior Medical Editor of The Lancet**, one of the world's most authoritative academic journals. This diverse group of experts is poised to exchange insights on a wide range of topics – from rare diseases to cancer detection and molecular diagnoses; from genomic data sharing to legal and ethical discussions; and from artificial intelligence (AI) to healthcare record management and scientific research.

The Opening Ceremony will be officiated by **Professor Lo Chung-mau, Secretary for Health of the Hong Kong SAR Government**. Setting the stage, Professor Lo will deliver a keynote address, laying the groundwork for a deep dive into genomic innovations and clinical applications. Dr Lo Su-vui, Chief Executive Officer of HKGI, and Alexandra Heumber Perry, Chief Executive Officer of RDI, will also join the Opening Ceremony to unveil the event.

Highlights of esteemed speakers include:

- **Professor Dennis Lo, Vice-Chancellor and President of The Chinese University of Hong Kong**, as well as **Board Member of HKGI**, will discuss cutting-edge applications of plasma DNA analysis.
- **Dr Brian Chung, Chief Medical and Scientific Officer of HKGI**, will share the journey of implementing Hong Kong Genome Project, the city's first large-scale whole genome sequencing (WGS) initiative aimed at propelling personalised medicine forward.
- **Professor Zhang Shuyang, President of the Peking Union Medical College Hospital** and pioneer in Mainland China's rare diseases programmes, will introduce respective models covering teaching, service and research.
- **Professor Kym Boycott from the University of Ottawa (Canada)** will focus on molecular pathogenesis of rare diseases that improve patient care and family well-being.
- **Professor Roberto Giugliani from the Federal University of Rio Grande do Sul (Brazil)** and a leading researcher in Latin American genetics, will share his perspectives on metabolic disorders.
- **Professor Bartha Knoppers from McGill University (Canada)** and an expert in genomics and biotechnology ethics, will discuss legal topics arising from genomic data sharing.
- **Professor Gareth Baynam from the Perth Children's Hospital (Australia)**, and **Professor Yong Chen from the University of Pennsylvania (USA)** will also offer insights on harnessing the latest technologies such as AI for clinical and healthcare records to inspire innovation.

Dr Lo Su-vui, Chief Executive Officer of HKGI said, "We are greatly honoured and excited to partner with RDI and LCRD, two world-leading institutions that share our vision of making genomic medicine available to all for better health and well-being. This Symposium, rich in depth and scope, marks a pivotal milestone in advancing genomic medicine through international collaborations. By bringing together global experts and showcasing Hong Kong's capabilities in genomic research and clinical applications, we are not only reaffirming our commitment to integrating genomics into routine patient care and inspiring ground-breaking research, but also contributing to Hong Kong's development as an International Health and Medical Innovation Hub."

Alexandra Heumber Perry, Chief Executive Officer of RDI added, "We are thrilled to partner with the Hong Kong Genome Institute on this important initiative to advance research on rare diseases and improve outcomes for Persons Living with Rare Diseases (PLWRD) around the world. This Symposium, which will bring together leading experts from more than 20 countries and regions, demonstrates our joint commitment to placing PLWRD at the centre of their own care, and to promoting health equity, human rights and access to treatment for PLWRD. Through the shared dedication and expertise of the experts from the RDI-LCRD and HKGI, we will work to ensure that PLWRD are seen, heard and cared for, no matter where they live."

The one-day Symposium is anticipated to attract close to 300 participants. For programme details, please refer to the Appendix. Following the Symposium, the annual LCRD Meeting will be held on 18-19 November 2025, which will further strengthen international cooperations in research and development of genomic medicine and rare diseases.

For enquiries about the Symposium, please contact HKGI (symposium@genomics.org.hk) or RDI-LCRD (lcrd@rarediseasesint.org).

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About Hong Kong Genome Institute

The Hong Kong Genome Institute (HKGI), established and wholly owned by the Hong Kong SAR Government, commenced full operations in 2021. With the vision “to avail genomic medicine to all for better health and well-being” and supported by the Health Bureau, HKGI works in close collaboration with the Department of Health, Hospital Authority, medical schools of local universities and other stakeholders to accelerate the development of genomic medicine in Hong Kong along four strategic foci: integrate genomics into medicine, advance research, nurture talents and enhance public genomic literacy.

As the first step towards achieving its vision, HKGI launched the Hong Kong Genome Project (HKGP) in 2021 focusing on diseases and research cohorts that would benefit from whole genome sequencing. They include undiagnosed diseases, hereditary cancers and cases related to genomics and precision health. Being the city’s first large-scale genome sequencing project, HKGP serves as a catalyst to benefit patients and their families with more precise diagnosis and personalised treatment. It also aims to establish genome database of the local population, testing infrastructure and talent pool to address the healthcare needs of Hong Kong in the long run.

For more information, please visit <https://hkgp.org/en>.

About Rare Diseases International

Rare Diseases International (RDI) is the global alliance of people living with a rare disease of all nationalities across all rare diseases. RDI’s mission is to be a strong common voice on behalf of rare disease patients around the world, to advocate for rare diseases as an international public health priority and to represent its members and enhance their capacities. RDI has more than 120 member organizations from 50 countries, which in turn represent rare disease patient groups in more than 150 countries worldwide.

For more information, please visit <https://www.rarediseasesinternational.org>.

About Lancet Commission on Rare Diseases

The RDI-Lancet Commission on Rare Diseases (RDI-LCRD) is a new initiative dedicated to improving the lives of Persons Living with a Rare Disease (PLWRD) globally by generating evidence-informed recommendations that can be implemented in all countries. The RDI-LCRD, chaired by Dr. Roberto Giugliani (Brazil) and Dr. Kym Boycott (Canada) brings together 27 Commissioners from 6 continents with a broad range of expertise, perspectives and experience. The overarching goal of the RDI-LCRD is to use robust data to ignite global action that will amplify the voices of PLWRD and ensure that they are seen, heard, and cared for, no matter where they live.



For more information, please visit <http://www.rarediseasescommission.org>.



[→ Please turn to the next page for details of the Symposium]

International Genomic Medicine Symposium
17 November 2025, Hong Kong
Charles K. Kao Auditorium, Hong Kong Science Park

Time	Programme	Speaker
09:00	Keynote	Prof Lo Chung-mau, BBS, JP Secretary for Health Hong Kong SAR Government Hong Kong, China
09:15	Opening Ceremony	
<u>Panel 1</u>		
09:30	Developing Rare Disease Models in China: Service, Teaching and Research	Prof Zhang Shuyang President Peking Union Medical College Hospital China
10:00	Unraveling Molecular Pathogeneses to Enhance Patient Care and Family Well-being	Prof Kym Boycott Co-Chair Lancet Commission on Rare Diseases Professor of Pediatrics University of Ottawa Canada
10:30	Panel Discussion	
10:45	Coffee Break	
<u>Panel 2</u>		
11:15	Insights into Rare Diseases: Focus on Inborn Errors of Metabolism	Prof Roberto Giugliani Professor of Genetics Federal University of Rio Grande do Sul Brazil
11:45	Hong Kong Genome Project Case Sharing (1): Ending the Diagnostic Odyssey	Hong Kong College of Physicians – Hong Kong Genome Institute Scholar Hong Kong, China
12:00	Hong Kong Genome Project Case Sharing (2): Whole Genome Sequencing Informs Personalised Treatment	Hong Kong Academy of Medicine – Hong Kong Genome Institute Scholar Hong Kong, China
12:15	Panel Discussion	
12:30	Lunch	

Panel 3		
14:00	Exploring Ethico-legal Issues in Genomic Data Sharing	Prof Bartha Knoppers Director Centre of Genomics and Policy McGill University Canada
14:30	Hong Kong Genome Project: Advancing the Genomics Frontier	Dr Brian Chung Chief Medical and Scientific Officer Hong Kong Genome Institute Hong Kong, China
15:00	Facilitating Drug Development in the Greater Bay Area International Clinical Trial Institute (GBAICTI)	GBAICTI Representative Hong Kong, China
15:30	Panel Discussion	
Panel 4		
15:45	AI in Action: The Journey from Clinical Record to Personalised Treatment	Prof Gareth Baynam Medical Director Rare Care Centre Perth Children's Hospital Australia
16:15	Harnessing the Power of Electronic Healthcare Records in Scientific Research and Innovation in Genomic Medicine	Prof Yong Chen Professor of Biostatistics University of Pennsylvania USA
16:45	Panel Discussion	
Panel 5		
17:00	Publishing at <i>The Lancet</i>	Dr Chloe Wilson Senior Medical Editor The Lancet
17:30	Keynote: Revolutionising Plasma DNA Analysis in Transforming Non-invasive Testing and Cancer Detection	Prof Dennis Lo, SBS, JP Vice-Chancellor and President The Chinese University of Hong Kong Board Member Hong Kong Genome Institute Hong Kong, China
18:00	Panel Discussion	
18:15	End of Symposium	

Enquiry  www.hkqp.org
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