



**Asia-Pacific
Economic Cooperation**

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Speaker Biographies

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**APEC Policy Dialogue on Rare
Diseases
Beijing, China
6-7 June 2018**

By Order of Appearance in the Program

Prof. Matthew Bellgard
Chair, APEC LSIF Rare Disease Network; Director, eResearch, Queensland University of Technology, Australia



Professor Bellgard is the inaugural eResearch Director at Queensland University of Technology. Previously, Professor Bellgard was the Director of the Centre for Comparative Genomics, a Western Australian State Government Centre of Excellence for over 12 years. As CCG Director, he was responsible for the expansion of the Centre into the fields of rare disease and molecular therapy. Professor Bellgard also serves as the Chair of the APEC Rare Disease Network to address the barriers to Healthcare Services for populations affected by rare diseases. His scientific work has resulted in developments in both the areas of pairwise sequence alignment and artificial intelligence, human genomics, bacterial bioinformatics, whole genome analysis and annotation for a range of species, as well as eResearch across a range of disciplines. Professor Bellgard co-leads development of digital infrastructure for funded collaborative research in adaptive platform trials that are of particular relevance for rapidly evaluating new therapies, which critically relies on quality health data linkage, patient engagement and reliable secure digital platforms that can operate across jurisdictions and health stakeholder business units.

Dr. Jakris Eu-Ahsunthornwattana, MD, PhD
Lecturer, Department of Community Medicine, Faculty of Medicine, Ramathibodi Hospital, Mahidol University



Dr. Jakris Eu-Ahsunthornwattana is a medical researcher at Mahidol University, specializing in technology in translational medicine. He received his PhD in statistical genetics from Newcastle University's Institute of Genetic Medicine in 2015. He researched the use of empirical (genotype-based) and theoretical (pedigree-based) identity-by-descent (IBD) estimates in genetic data analysis of large pedigrees. Dr. Jakris also holds an M.D. from Faculty of medicine Ramathibodi Hospital of Mahidol University and an MSc in Epidemiology: Principles and Practices from the University of London's School of Hygiene and Tropical Medicine.

Mr. Cameron Milliner
Industry Co-Chair, APEC LSIF Rare Disease Network; Head, Public Affairs & Patient Advocacy – Asia Pacific, Shire



With more than 15 years of experience within government, consultancy and multinational corporations, Cameron has a deep understanding of the development and implementation of public policy, stakeholder management and advocacy.

He currently works as the Head Public Affairs and Patient Advocacy for Shire, a biopharmaceutical company specialising in rare and specialty conditions, with responsibility for the Asia Pacific Region. Prior to this, Cameron worked for a Pharmaceutical and Medical Device Company, as a Director of a Corporate Affairs consultancy and as a Senior Advisor to a Health Minister in an Australian State Government. Cameron holds a Bachelor of Commerce (Marketing and Industrial Relations) from Griffith University and has been appointed a Visiting/Honorary Fellow of the Murdoch University School of Research and Innovation and the Centre for Comparative Genomics. In addition to these roles he also holds an Honorary Fellowship of the McKell Institute, a public policy think tank specialising in social policy.

Dr. Jean-Luc Lowinski, PhD, MBA
Head of Emerging Markets, Sanofi Genzyme

Jean-Luc Lowinski became Senior Vice President, Sanofi Asia on May 1st, 2012. In this role, Dr. Lowinski is responsible for Sanofi's business and growth in Greater China, Southeast Asia (Philippines, Thailand, Indonesia, Singapore/Malaysia), and Indochina (Vietnam, Laos, Cambodia). In January 2017, Jean-Luc Lowinski took on the responsibility of Sanofi Genzyme



Emerging Markets based out of Paris. Prior to joining Sanofi, Dr. Lowinski built a successful career in Pharmaceuticals, Consumer Healthcare and Animal Health. He began his career in the French Army as a technical volunteer before becoming a veterinary. He joined Bayer Germany in 1992 and held various positions including Head of Operations in Singapore, India, Thailand, China and Japan. In 2003, he became Head of Bayer Healthcare, China. He then became Head of Bayer Healthcare, Asia Pacific, at the end of 2004 before being appointed President, Bayer Yakuhin, Japan in 2007. In 2010, he became Global Head of the Animal Health Division at Bayer. Dr. Lowinski holds a Ph.D. in Veterinary Science from the University of Nantes, France and is a graduate from INSEAD. He is a French national, and he speaks French, English, German, Japanese and Chinese.

Dr. Durhane Wong-Rieger,
Chair, Rare Diseases International; President & CEO,
Canadian Organization for Rare Disorders

Dr. Wong-Rieger is President & CEO of the Canadian Organization for Rare Disorders, the umbrella organization of patients and patient groups, and chair of the Consumer Advocare Network, a national network for patient engagement in healthcare policy and advocacy. She is also President & CEO of the Institute for Optimizing Health Outcomes, providing training and direct service on health coaching and patient self-



management. Dr. Wong-Rieger has served on numerous health policy advisory committees and panels and is a member of the Advisory Board for the Canadian Institutes of Health Research Institute of Genetics and the Patient Liaison Forum for the Canadian Drugs and Technologies in Health. Internationally, Dr. Wong-Rieger is immediate Past-Chair of the International Alliance of Patient Organizations, Board Member representing patient interests

at DIA International Association, Steering Member of the Health Technology Assessment International Patient/Citizen Involvement Interest Group and Secretary of the Asia Pacific Alliance of Rare Disease Organizations. Dr. Wong-Rieger is a certified Health Coach and licensed T-Trainer with the Stanford-based Living A Healthy Life with Chronic Conditions. Dr. Wong-Rieger has a PhD in psychology from McGill University and was professor at the University of Windsor, Canada from 1984-1999.

Mr. Andrew Martin
Vice President, Marketing - Rare Disease: Latin America, Asia-Pacific, Africa/Middle East, Pfizer

Andrew Martin assumed the role of Pfizer's Vice President of Marketing for Rare Disease in Latin America, Asia-Pacific, Africa/Middle East in January 2018. He also serves as the Senior Director of Regional Therapeutic Area Lead in Latin America. In that role, he is accountable for the Therapeutic Area (Vaccines) in Latin America the team of country and regional marketers as well as cross-functional partners to achieve financial targets. He simultaneously serves as the Senior Director of US Vaccines Marketing. Before joining the Pfizer team in 2006, Martin worked for Janssen, Pharmaceutical Companies of Johnson and Johnson and Fiskars Brands. He graduated from the University of Pittsburgh with a BA in Political Science and East Asian Studies and from Cornell University's S.C. Johnson Graduate School of management with his MBA.



Dr. Shuyang Zhang
Vice President and Director of Clinical Pharmacology Research Center, Peking Union Medical College Hospital

Dr. Shuyang Zhang serves as the Vice President of Peking Union Medical College Hospital and Director of Clinical Pharmacological Research Center in PUMCH. Prior to this, professor Zhang was Deputy Director of Cardiology Department in PUMCH. Dr. Shuyang Zhang has authored and co-authored several national and international publications and works as a reviewer for reputed professional journals. She was a postdoctoral fellow in Ochsner Health System from 1995 to 1999. Dr. Zhang obtained her bachelor degree in Beijing Medical University in 1986 and was recommended for a five-year doctoral program in Peking Union Medical College (PUMC).



Mr. Luke Elias
Director, Business Analytics & Performance, Blacktown & Mount Druitt Hospitals, Western Sydney Local Health District, Australia

Luke Elias is the Director of Business Analytics & Performance within Western Sydney Local Health District in New South Wales, Australia. Luke has worked extensively in clinical



capacity, health management and administration roles in both the public and private sector over the past 2 decades. He has held senior management and operational positions within the NSW public health system is dedicated to working collaboratively with health professionals and administrators. Luke commenced his health career in 2001 as a Physiotherapist and is currently responsible for operational performance management of two public hospitals in one of the fastest growing, ethnically diverse populations within Australia.

He is passionate about provision of best practice service delivery to improve health outcomes and patient experiences, and doing so with a strong understanding of efficient resource utilisation and the operational design requirements critical to large scale health service innovation, redesign, reform and sustainable change. He has a particular interest in timely access to appropriate health care, chronic and complex disease management, improving health system literacy and fostering consumer advocacy to deliver patient centred models of care.

Mr. Hyun Min Shin
Chairman, Korean Organisation for Rare Diseases, Republic of Korea

In addition to serving as the Chairman of the Korean Organisation for Rare Diseases (KORD) since 2001, Mr. Hyun-Min Shin is also an advisory committee member of Korea Orphan & Essential Drug Center Drug Center (KODC). Mr. Shin previously served as a committee member of Export the department for rare medical device in Korea Food & Drug Administration (KFDA), We Start Movement Headquarters, rare disease patient`s center in Korea Centers for Disease Control and Prevention (KCDC), and medical support project for rare disease patients in the Ministry of Health & Welfare (MW). For his contributions, Mr. Shin has received numerous awards, most notably a volunteer service award for The 21st Gil prize by Women doctors by the Korean Medical Women`s Association in 2011, a merit of National Healthcare business for The 37th Health Day in 2009, and a merit of medical support project for rare disease patients in 2006.



Mr. Kevin Huang
President, Founder & President, Chinese Organization for Rare Disorders

Kevin graduated from Zhejiang University in 2006, with a major in advertising. As a rare disease patient, Kevin is very committed to rare disease communities and has conducted in-depth studies of public service industry and public policy in China since 2003, when he began to be interested in this area. Before he co-founded China-Dolls Center for Rare Disorders, he worked as a specialist and advocate for human rights of people affected by HIV/AIDS. When he co-founded China-Dolls Center for Rare Disorders in 2008, the concept of “rare disease” was still unknown in China and the rare disease communities were invisible in the society. He has successfully made “rare disease” well-known to millions of people in the past four years. Kevin also forges ahead with developing the rare disease network, and providing training and



educational opportunities for rare disease patient groups. Until now, there are over 50 rare disease organizations in the network. In 2012, Kevin successfully localized International Rare Disease Day in China and makes it a leader brand in the non-profit sector. In 2013, he founded Chinese Organization for Rare Disorders, the only organization representing all types of rare diseases in China. Chinese Organization for Rare Disorders has achieved great social impact throughout the country and Kevin's leadership and efforts have been recognized and acclaimed by the public.

Mr. Peter Fang
Regional Head – APAC, Shire

Peter Fang is Head of Asia Pacific at Shire, a leading global biotechnology company focused on rare diseases and specialty medicines. Peter has responsibility for Shire's operations in the region, with headquarters in Singapore. Prior to Shire, Peter spent over 14 years at Baxter / Baxalta's Hematology and Immunology divisions in a variety of global, regional, and country commercial roles in the United States, Switzerland, and the UK. He was most recently responsible for commercial operations in over 40 small- and mid-sized markets across Europe, Middle East, and Africa.



Peter is from Chicago, Illinois and has a degree from the Wharton School of the University of Pennsylvania. With a passion for Singapore as the business hub for the Asia Pacific region, Peter is committed to ensuring Singapore continues to embrace and celebrate the role of businesses with significant United States interests as part of its commercial fabric and economic future.

Dr. Duangrudee Wattanasirichaigoon
Professor of Pediatrics & Medical Genetics and Chief of Division of Medical Genetics, Department of Pediatrics, Faculty of Medicine, Ramathibodi Hospital, Mahidol University, Thailand

Duangrudee Wattanasirichaigoon is Professor in the Faculty of Medicine at Ramathibodi Hospital at Mahidol University in Bangkok, Thailand. Dr. Duangrudee is a pediatrics specialist. She co-founded the Thai Rare Disease Foundation and is affiliated with the Thailand Rare Disease Network. Dr.



Duangrudee's research interests include study on molecular genetics of congenital deafness; study on molecular genetics of rare diseases, deformities, and inherited metabolic disorders; and citrin deficiency and its genetic epidemiology, prevalence, roles in tropical diseases, and molecular study and mechanism.

Dr. Eva Maria C. Cutiongco-De La Paz
Vice Chancellor for Research & Executive Director, National Institutes of Health, University of the Philippines-Manila

Dr. Eva Maria C. Cutiongco-De La Paz, MD, FPPS, is Vice Chancellor for Research, University of Philippines Manila,



Executive Director, National Institutes of Health and Program Director for Health, Philippine Genome Center, University of the Philippines. Dr. Cutiongco-De La Paz received her Bachelor of Science degree in biology at the UP College of Science in 1984. She finished her Doctor of Medicine degree from the UP College of Medicine in 1989, and completed her pediatric residency at the Philippine General Hospital in 1992. She received awards as an outstanding intern and most outstanding resident in pediatrics in the same institution. Dr Cutiongco-De La Paz was a Ten Outstanding Young Men (TOYM) awardee for the field of Genetic Medicine in 2002, and was also recognized by the National Academy of Science and Technology as one of the Outstanding Young Scientists (OYS) in the same year. She was also recognized as one of the Outstanding Women in the Nation's Service (TOWNS) for medicine in 2007. She received the 2011 UP Manila's Outstanding Researcher and the Professorial Chair for Excellence in Teaching and Research in Pediatrics and Genetics.

Dr. Yin-Hsiu Chien

Department of Pediatrics and Medical Genetics, Taiwan University Hospital, Chinese Taipei



Dr. Yin-Hsiu Chien graduated from Chang Gung Medical School and obtained her PhD from Taiwan University. She undertook pediatric residency training at Taiwan University Hospital, and completed her fellowship in Pediatric Allergy, immunology, and rheumatology before she completed her fellowship in Medical Genetics and Metabolism both at Taiwan University Hospital. Dr. Chien has made diverse contributions in the field of inborn errors of metabolisms and primary immunodeficiency, publishing over 50 original research articles in last 5 years. She is director of newborn screening center at Taiwan University Hospital, which routinely screens around one third of newborn infants in Taiwan. Her team, led by Dr. Wuh-Liang Hwu, is devoted to the diagnosis and treatments of several metabolic disorders including phenylketonuria, Niemann-Pick C disease, and aromatic l-amino acid decarboxylase deficiency. She is currently focusing on Pompe disease, specifically on early diagnosis and improvement of treatment, as well as on early diagnosis of severe immunodeficiency.

Dr. Joan Keutzer, Ph.D.

Moderator, Vice President and Head, Integrated Solutions, Rare Diseases Franchise, Sanofi Genzyme, Sanofi



Joan Keutzer is Vice President and Head of Integrated Solutions for Rare Diseases at Sanofi Genzyme. She is a member of the National Tay-Sachs and Allied Diseases Corporate Advisory Council, and has served as an advisor the Lysosomal Storage Disorder Network, the American College of Medical Genetics LSD Newborn Screening workgroup, and several NIH initiatives on rare diseases. Joan joined Genzyme Diagnostics in 1995, and in 1998, she became involved in the development of therapies for Fabry disease, MPS I and Pompe disease. Joan has had many roles at Genzyme, including managing the early stage R&D portfolio, running an R&D group focused on diagnostic assays and newborn screening, and establishing Scientific Affairs. Before joining Genzyme, Joan was a post-doctoral

research fellow at Beth Israel Deaconess Medical Center and the Harvard Medical School. She received her Ph.D. in cellular and molecular biology from the University of Kentucky, School of Biological Sciences, and her B.S from Northern Kentucky University.

Dr. Elena Nicod, Ph.D.

Senior Consultant, Dolon Ltd; Co-Leader of IMPAC-HTA Work Package 10 on Appraisal of Orphan Medicinal Products, Bocconi University, Italy



Elena Nicod is Research Fellow at the Bocconi University, Centre for Research on Health and Social Care Management (CERGAS) in Milan, Italy. Dr. Nicod also serves as a member of the European Working Group for Value Assessment and Funding Processes in Rare Diseases (ORPH-VAL). ORPH-VAL is a working group of European rare disease experts that was formed in 2015. It comprises of patient representatives, academics, politicians, regulators, payers and industry. The group was formed to improve patient access to orphan medicines through the formation of common principles to underpin P&R processes in Europe. After several months of work, the group published recommendations on patient improved access to orphan medicines in the Orphanet Journal of Rare Diseases under the title: “Recommendations from the European Working Group for Value Assessment and Funding Processes in Rare Diseases”. Dr. Nicod was previously a Research Officer at the London School of Economics. Dr. Nicod holds a PhD in Social Policy from the London School of Economics.

Dr. Jie Ding

Member of the National Committee of the CPPCC; Professor of Pediatric Department, Peking University First Hospital; and Chairman, Rare Disease Branch, Beijing Medical Association



Dr. Ding is a Member of the National Committee of the CPPCC, Professor of the Pediatric Department at Peking University First Hospital, and Chairman of the Rare Disease Branch at the Beijing Medical Association. She is also Vice-President of the Peking University First Hospital. Dr. Ding is also a member of the International Pediatric Association, the Asian Society of Pediatric Nephrology, and the Chinese Society of Pediatric Nephrology. She received a M.D. from Beijing Medical College, a Ph.D. from the University of Minnesota and from the Beijing Medical University.

Mr. Prasanna Shirol

Co-Founder & Executive Director, Organization for Rare Disease India



Prasanna Shirol serves as a founder member of the Organization for Rare Diseases in India and a Founder Former President of LSD Support Society (Lysosomal Storage Disorder Support Society), This is the first National Level Parents support group for children suffering from ULTRA RARE Diseases in India. The society initiated observing International Rare Disease day for the first time

in India on a national scale under his leadership. He has worked extensively to create awareness on LSD and Rare disease in India. He has represented India in various conferences and meetings internationally and developed a strong network of international Parent and Rare disease groups. Prasanna has a Post Graduate in Business Management and over 16 years of sales experience in telecom and consumer industry. He worked with companies like Sony, Reliance, and Bharti. He has experience in launching product and services.

Dr. Vinciane Pirard

Co-Chair, Joint Task Force on Rare Diseases & Orphan Medicinal Products, European Federation of Pharmaceutical Industries & Associations

Vinciane is the co-chair of the joint task force on rare diseases and orphan medicinal products between the European Federation of Pharmaceutical Industries and Associations (EFPIA) and the European Association of Bioindustries (EuropaBio). Previously, she worked 8 years in Genzyme medical department on diagnosis, registries and product development for rare genetic diseases. She also worked at Solvay Pharma and Wyeth.



Prof. John CW Lim

APEC LSIF Board Member; Executive Director, Duke-NUS Centre of Regulatory Excellence; Chairman, Singapore Clinical Research Institute, Singapore

Prof John CW Lim brings a wealth of experience in public health and management to CoRE. Prof Lim draws on his long-standing international expertise and networks to enhance regulatory capacity and scientific excellence in the Asia-Pacific, having served in leadership roles in numerous public health agencies. Prof Lim is a medical graduate of the National University of Singapore (NUS), and holds Masters Degrees in Public Health from NUS and in Health Policy and Management from Harvard University. He is a Specialist in Public Health Medicine, a Fellow of the Singapore Academy of Medicine, and Adjunct Associate Professor at the NUS Saw Swee Hock School of Public Health and the Duke-NUS Graduate Medical School in Singapore. In the course of his career, he has served as Administrator of the Singapore Blood Transfusion Service, Special Assistant to the Permanent Secretary for Health & Director of Medical Services, Deputy Medical Director of the Institute of Mental Health, and Director, Human Resource in Singapore's Ministry of Health (MOH). He has also been Director of Higher Education and Director of Public Affairs in the Singapore Ministry of Education. Following the establishment of the Health Sciences Authority (HSA), Prof Lim became Director of its Centre for Drug Administration. He was appointed HSA's Chief Executive Officer in 2006 and led the organisation for eight years during a period of major development and growth. In July 2014, Dr Lim assumed the concurrent appointments of Deputy Director of Medical Services (Industry & Research Matters) in MOH and Executive Director of the Centre of Regulatory Excellence (CoRE) at the Duke-NUS Graduate Medical School, Singapore.



Dr. Kyu-Been Sohn
Asia Regional Regulatory Strategist, Pfizer

Dr. Kyu-Been Sohn is the Asia Regional Regulatory Strategist for Pfizer, a position held since 2013 based in Korea. Prior to her appointment to this position, Dr. Sohn was the Senior Regulatory Affairs Associate at Pfizer Korea. Her expertise spans regulatory submissions to regulatory requirements.

Ms. Eileen Ang
Head of Regulatory Affairs – APAC, Shire

Ms. Ang has more than 20 years of experience handling regulatory affairs in the Asia Pacific region involving a wide range of products including pharmaceuticals and biologicals/vaccines in different therapy areas. She has lobbied and shaped regulatory environment to overcome challenges and delivered registration approvals in China, Taiwan, Korea and Vietnam. This includes her leadership in registering 8 biologics across the region in 4 therapy areas and an MS drug in China. Prior to joining Shire, Ms. Ang was the Head of Regulatory Affairs in Asia Pacific at GSK for 6 years and Director, Asia Pacific at Merck Serono for 13 years.



Camila Quirland Lazo, PharmD, MSc.
Unit Chief, Health Technology Assessment, Oncology Institute,
Arturo Lopez Perez Foundation, Chile

Camila is a Pharmacist from the University of Chile, she has a Master in Pharmaceutical Science degree from the same University and postgraduate studies in health technology assessment and pharmacoconomics. Sin 2012 her research field have been rare diseases policies, with special focus on the insurance arrangements and health technology assessment processes for orphan drugs. She has presented her work in this area on different ISPOR conferences and she also participates on different ISPOR Rare Diseases Special Interest Groups.



From 2014 to 2017 Camila was researcher and academic coordinator of the pharmacoconomics and health technology assessment Diploma in the Pharmacoconomics and Health Economics Unit, at the University of Chile's Public Health School. Also, from 2015 to 2018 Camila was Consultant in the Economics and Bussiness Faculty in the University of Chile, specifically in the Institute of Health Administration. She is also Invited Professor in different Evidence Based Medicine and Pharmacoconomics courses for undergraduate and graduate pharmacy students in the University of Chile and academic coordinator of the first one. Since 2017 she is ISPOR Chilean Chapter President. Since the present year, she is Head of the Health Technology Assessment Unit in the Oncology Institute, Arturo López Pérez Foundation.

Ms. Julie Kim
Global Franchise Head, Hematology, Shire

Julie Kim was previously Head of International Value Demonstration & Access for Shire. Prior to Shire's acquisition of the companies, Julie held a diverse number of senior leadership roles in Baxalta & Baxter, including Head of Business Model Innovation, North/South Europe Cluster Head for Immunology, General Manager for Baxter UK/Ireland & Global Franchise Head for BioTherapeutics. She began her Baxter career in 2001 & over the next 10 years, she advanced through positions of increasing responsibility in various functions. Prior to joining Baxter, Julie worked in healthcare consulting for over seven years. Julie was a 2013 HBA Rising Star. She has an MBA from the J. L. Kellogg Graduate School of Management at Northwestern University and a BA in Economics from Dartmouth College. She is married and has two children.



Dr. Gong Mengchun
Executive Director, National Rare Disease Registry System of China

Graduated from Peking Union Medical College with a Medical Doctor degree in 2011, Dr. Gong Mengchun entered PUMC Hospital and accomplished the internal residency training, during which period he also worked in University of California, San Francisco as a visiting scholar. From 2016, He took the position of the Executive Director of the National Rare Diseases Registry System of China and started to lead the team, composed of over 20 medical institutes in China, to build this nation-wide patient registry system for more than 50 kinds of rare diseases, aiming to recruit over 50, 000 cases in 5 years. Dr. Gong also hold the position of Medical Informatics Consultant for the Translational Medicine Center of Fudan University, Children's Hospital, which is ranked as the National Center for Children's Care of China and is one of the leading institutes to provide medical genetics consultancy service to inherited diseases. The major research area of Dr. Gong is medical informatics, covering the directions of ontologies/terminologies, clinical natural language processing, phenotyping based on EMR, integration of phenome and biological omics data and the further data mining. From 2017, Dr. Gong started his standing as one of the seven directors in the management board of SNOMED International, which is the leading clinical terminology organization worldwide.