

# 香港唐氏綜合症協會 三十周年研討會

## HKDSA 30<sup>th</sup> ANNIVERSARY SYMPOSIUM

創新、創見、創將來  
Innovation, Insights & Intervention

從醫學研究、醫療服務、早期教育到照顧歷程  
的分享，認識唐氏綜合症。

語言 Language: 廣東話 Cantonese



### 唐氏綜合症無創傷性產前診斷：從夢想到實現

Non-invasive Prenatal Testing of Down Syndrome: From Dream to Reality

主講 Presented by

**盧焜明教授** Professor Dennis LO Yuk Ming

香港中文大學李嘉誠健康科學研究所所長  
Director, Li Ka Shing Institute of Health Sciences,  
The Chinese University of Hong Kong



### 遺傳學家的故事 – 與唐氏人士的互動生命歷程

Story-telling in Clinical Genetics – Patients that changed my life as a clinical geneticist

主講 Presented by

**鍾佩言醫生臨床副教授** Dr. Brian CHUNG Hon Yin

香港大學李嘉誠醫學院兒童及青少年科學系婦產科學系臨床副教授  
Clinical Associate Professor, Centre for Reproduction, Development and Growth,  
Department of Paediatrics and Adolescent Medicine, Department of Obstetrics and Gynaecology,  
The University of Hong Kong



### 支援智障學生在普通學校學習

Supporting the learning of students with intellectual disabilities in mainstreaming schools

主講 Presented by

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香港教育大學特殊學習需要與融合教育中心總監  
Director, Centre for Special Educational Needs and Inclusive Education,  
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### 生命號，啟航吧！

"Life Voyage" Let's Set Sail!

分享 Shared by

**楊映梅女士** Ms. Maggie YEUNG Ying Mui

香港唐氏綜合症協會家長委員會主席  
Chairlady, Parents Committee,  
The Hong Kong Down Syndrome Association

研討會設有  
問答時間

Q & A session will be arranged after  
all presentations finish

網上報名  
Online  
Registration



www.hk-dsa.org.hk/30-ann-symposium/registration  
截止日期Deadline: 2017.6.9

6/24  
2017  
Saturday  
10a.m.-1p.m.

沙田威爾斯親王醫院香港中文大學深造中心  
CUHK, Postgraduate Education Centre, Prince of Wales Hospital, Shatin, N.T., H.K.

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專業學分  
登記查詢  
CME, CNE,  
CPD, CEPST  
Professional  
Accreditation



演講摘要及講者介紹  
Presentation Abstract & Speakers' Biography



# 香港唐氏綜合症協會 三十周年研討會

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### 創新、創見、創將來 | Innovation, Insights & Intervention



#### 盧煜明教授

*Professor Dennis LO Yuk Ming*

香港中文大學醫學院副院長(研究)及  
李嘉誠健康科學研究所所長  
Associate Dean (Research) of Faculty of Medicine and  
Director of Li Ka Shing Institute of Health Sciences  
The Chinese University of Hong Kong

盧煜明教授現為香港中文大學醫學院副院長(研究)、李嘉誠健康科學研究所所長及化學病理學系系主任。盧教授於英國劍橋大學取得文學士學位，再於牛津大學取得醫學博士及哲學博士學位。

在1997年，盧教授成為世界上第一位科學家發現母體血漿內有胎兒的去氧核糖核酸(DNA)，從而開闢了一個新研究領域，並致力於有關方面的研究。盧教授所帶領的研究團隊已率先研發出無創性產前診斷服務，透過先進的DNA測序技術，直接從母親的血液樣本中，包括胎兒基因組、甲基化及轉錄組排序進行分析以檢測唐氏綜合症，及利用游離核酸進行癌症診斷等多種新技術。為彰表其科學研究成就，盧煜明教授先後獲授英國皇家學會院士榮銜、美國國家科學院外籍院士榮銜、世界科學院院士、及港科院創院院士。盧教授亦曾獲頒其他各項獎項，包括2016未來科學大獎生命科學獎、2014年度費薩爾國王(King Faisal)國際醫學獎，及2012年度的里雅斯特獎(Ernesto Illy Trieste Science Prize)。

Professor Dennis Lo is the Director of the Li Ka Shing Institute of Health Sciences, the Li Ka Shing Professor of Medicine and Professor of Chemical Pathology of The Chinese University of Hong Kong (CUHK). He is also the Associate Dean (Research) of the Faculty of Medicine of CUHK. Dennis Lo received his Bachelor of Arts degree from the University of Cambridge and Doctor of Medicine and Doctor of Philosophy degrees from the University of Oxford.

His research interests focus on the biology and diagnostic applications of cell-free nucleic acids in plasma. In particular, he discovered the presence of cell-free fetal DNA in maternal plasma in 1997 and has since then been pioneering non-invasive prenatal diagnosis using this technology. He has also made many innovations using circulating nucleic acids for cancer detection. In recognition of his work, Professor Lo has been elected as Fellow of the Royal Society, Foreign Associate of the US National Academy of Sciences, Fellow of The World Academy of Sciences (TWAS) and Founding Member of the Academy of Sciences of Hong Kong. Professor Lo has won numerous awards, including the 2016 Future Science Prize in Life Science, the 2014 King Faisal International Prize in Medicine and the 2012 Ernesto Illy Trieste Science Prize from TWAS.



#### 鍾侃言醫生臨床副教授

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瑪麗醫院兒童及青少年科學系榮譽顧問醫生  
Clinical Associate Professor, Centre for Reproduction, Development and Growth, Department of Paediatrics and Adolescent Medicine, Department of Obstetrics and Gynaecology, The University of Hong Kong  
Honorary Consultant, Department of Paediatrics and Adolescent Medicine, Queen Mary Hospital

鍾侃言，香港大學李嘉誠醫學院臨床副教授，並擔任瑪麗醫院、贊育醫院及大口環根德公爵夫人兒童醫院的兒科及婦產科榮譽顧問醫生。鍾醫生畢業於香港大學，獲授內外全科醫學士學位(榮譽學位)及兒科專科院士資格後，赴加拿大多倫多The Hospital for Sick Children深造，於遺傳學部門積累臨床及研究的工作經驗，並在2010年取得Canadian College of Medical Geneticists的院士資格。鍾醫生是現時唯一在香港醫管局轄下工作的臨床遺傳學家。除此之外，鍾醫生也是香港大學遺傳輔導碩士課程的主任導師。鍾醫生熱心於醫學研究，其主要研究方向包括：一、表觀遺傳學(epigenetics)，二、臨床遺傳學(clinical genetics)，及三、基因組技術的臨床應用(clinical application of genomic technologies)。鍾醫生經已在國際醫學期刊發表了超過50篇關於臨床遺傳學的醫學論文，並被邀請在香港、亞洲及世界各地作了多次公開演講。

Dr Brian Chung obtained his medical degree with honors from the University of Hong Kong in 1999. He became a Fellow of The Hong Kong College of Paediatrician in 2006 and a Fellow of the Canadian College of Medical Geneticists in 2010. He is a Clinical Associate Professor / Honorary Consultant in the Department of Paediatrics and Adolescent Medicine and the Department of Obstetrics & Gynaecology of the University of Hong Kong. Dr Chung takes care of patients and families with genetic disorders. He has significant contribution in the establishment and teaching of a Master of Medical Science course in Genetic Counseling in HKU. A clinical geneticist and academic paediatrician by training, he focuses on accurate delineation of the clinical phenotype / natural history of genetic syndromes and how genetic and epigenetic factors contribute to disease susceptibility, using state-of-the-art genomic technologies.





## 冼權鋒教授

*Professor Kenneth SIN Kuen Fung*

香港教育大學特殊學習需要與融合教育中心總監  
Director, Centre for Special Educational Needs and Inclusive Education,  
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冼權鋒教授為香港教育大學特殊學習需要與融合教育中心總監，亦為特殊教育與輔導學系教授。他的學術專長和研究範疇包括支援有特殊教育需要學生及融合教育專業發展。他經常就本港的研究計劃及內地和澳門的特殊教育師資培訓提供顧問意見，亦成功獲得多項與特殊教育有關的研究項目及委託培訓課程。

冼教授亦積極參加多種與特殊教育和融合教育有關的社會服務，包括出任多間特殊學校的校董；應邀加入教育局、課程發展處、香港考試及評核局及社會福利署等政府機構轄下有關資優教育、融合教育、特殊教育及兒童事務等工作小組；同時亦擔任多個非政府機構的執行委員、小組委員或主席，為特殊幼兒、視障人士、聽障人士、智障人士、自閉症人士及有行為困難青少年等，提供專業服務。

近年來，冼教授屢獲研資局優配研究金，開展不同專題的研究，如主流學校自閉學生的教與學、融合生高中後的發展、教學助理的支援角色及融合生與非融合生家長的態度，特教生涯規劃教育的影響。此外，冼教授透過不同的資助項目，分別為主流中小學提供校本支援，為職前教師提升特教知能體驗及為內地特殊教育教師提供到港的特殊教育訓練。

Professor Kenneth Sin is the Director of the Centre for Special Educational Needs and Inclusive Education and the Professor in the Department of Special Education and Counselling at The Education University of Hong Kong in Hong Kong. His expertise and research lie in the area of supporting students with special educational needs and professional development in inclusion.

He has great consultancy experience in many local research projects as well as the training work for teachers teaching children with disabilities in Mainland China and Macau. He also takes part in many community activities, in relation to special needs and inclusion. He was invited to be the school council members of some special schools, members in some task groups for giftedness, inclusion, special needs and child welfare in Education Bureau, Curriculum Development Institute, Hong Kong Examination Assessment and Authority and Social Welfare Department.

He is also appointed as the executive members, committee members or chairs in many NGOs for serving kids with special educational needs, persons with visual impairment, hearing impairment, intellectual disabilities, autism and behavioral difficulties. He is leading a number of research funded by GRF for special needs and projects for school based support in inclusive schools, teacher empowerment in BEd programs and special needs training in China.



## 楊映梅女士

*Ms. Maggie YEUNG Ying Mui*

香港唐氏綜合症協會家長委員會主席  
Chairlady, Parents Committee,  
The Hong Kong Down Syndrome Association

楊女士是一名全職的事業女性，並育有兩名子女，其中兒子是一位15歲的唐氏綜合症年青人。楊女士自2002年開始加入香港唐氏綜合症協會，並於2014年被選成為家長委員會主席，及成為協會的執行委員會成員和服務委員會成員，以家長的身份為協會服務提供意見及服務監察。楊女士一直關注唐氏人士及智障人士的福祉，於協會、各家長平台及相關政府部門都積極為家長和子女發聲。

Ms. YEUNG has a profession in the full-time workforce and is a mother of two children. Her son aged 15 is the people with Down Syndrome. She joined HKDSA since 2002 and was elected to be the Chairlady of Parents Committee in 2014. Since then, she becomes a member of Executive Committee and Service Committee in HKDSA and provides consultation and governance on services development. Ms. YEUNG concerns very much on the well-being of people with Down Syndrome and Intellectual Disability, and her effort is being recognized by HKDSA, parents, and government.



## 唐氏綜合症無創傷性產前診斷：從夢想到實現

Non-invasive Prenatal Testing of Down Syndrome: From Dream to Reality

主講 Presented by  
**盧耀聰教授 Professor Dennis LO Yuk Ming**

香港中文大學李嘉誠健康科學研究所所長  
Director, Li Ka Shing Institute of Health Sciences, The Chinese University of Hong Kong

產前診斷是現代醫學不可或缺的一種技術。可惜，傳統的創傷性產前診斷往往會為胎兒帶來各種危機。在過去的許多年裡，世界各地的科學家一直夢想如何可以研發出無創傷性產前診斷的技術。在這個講座中，我將會向大家揭示我如何從一個醫學生的身份走上研究無創傷性產前診斷的道路，更會分享在過去逾二十年裡，我和我的研究團隊如何將夢想變成事實。我亦會跟大家討論關於這項突破性技術發展的一些道德、社會、和法律問題。

Prenatal testing is an established part of modern healthcare. However, conventional invasive methods for prenatal testing are associated with risks to the fetus. For many years, scientists around the world have been dreaming about the possibility of non-invasive prenatal testing. In this talk, I would describe my personal journey of entering this field as a medical student and how over a period of over two decades, moving this dream into reality. I would also discuss some of the ethical, social and legal issues associated with this revolutionary technology.

## 遺傳學家的故事 – 與唐氏人士的互動生命歷程

Story-telling in Clinical Genetics – Patients that changed my life as a clinical geneticist

主講 Presented by  
**鍾佩雲醫生臨床副教授 Dr. Brian CHUNG Hon Yin**

香港大學李嘉誠醫學院兒童及青少年科學系婦產科學系  
Clinical Associate Professor, Centre for Reproduction, Development and Growth, Department of Paediatrics and Adolescent Medicine, Department of Obstetrics and Gynaecology, The University of Hong Kong

在照顧一些有不同遺傳基因狀況如唐氏綜合症的兒童和家庭個案時，臨床遺傳學家在多個醫療學科團隊中便是重要的一員。人類一向都是透過敘述去描述現實、解讀事件及為自己和相關經驗賦予意義(Narrative and the Practice of Medicine: 2000 – by Brian Hurwitz, the Lancet)，若能從患者的故事中獲取、吸收和解讀相關經驗，將有助推動和加強醫生及患者的關係，使醫療工作更加人性化。在這個講座中，我將分享唐氏人士的故事如何改變了我作為一位從事兒科及教學臨床遺傳學家的生命。

Clinical Geneticists are important members of the multidisciplinary medical team who take care of children and families with different genetic conditions, including Down syndrome. Human beings are storytelling animals, and narrative is the most compelling from by which we recount reality, understand events and through which we make sense of our experience and ourselves (from Narrative and the Practice of Medicine: 2000 – by Brian Hurwitz, the Lancet). The ability to acknowledge, absorb, interpret, be moved and finally to act on patient's stories helps to strengthen the doctor-patient relationship and help to make the practice of medicine more humane. In this session, I shall share a few stories that have changed my life as a paediatrician practicing, teaching and learning clinical genetics in Hong Kong.

## 支援智障學生在普通學校學習

Supporting the learning of students with intellectual disabilities in mainstreaming schools

主講 Presented by  
**冼權鋒教授 Professor Kenneth SIN Kuen Fung**

香港教育大學特殊學習需要與融合教育中心總監  
Director, Centre for Special Educational Needs and Inclusive Education, The Education University of Hong Kong

融合教育發展至今，全港已有四萬多名有特殊學習需要的學生就讀於普通學校內。根據政府統計，約有千名輕度智力障礙學生就讀於融合學校。由於智障學生的學習特性及困難，學校需要進行不同方面的支援。本文將就「支援智障學生在普通學校學習意見調查」的結果，分析學校在課程編排、課程實施、教學支援、考評安排和成長支援等方面，如何支援及協助智障學生學習，並提出改善建議及教學支援策略。

Following the development of inclusive education in Hong Kong, over 40,000 students with special educational needs are studying in mainstreaming schools. According to the government statistics, about 1000 students with mild intellectual disabilities are identified in the inclusive settings. In regard to their feature and learning difficulties, schools have to offer a variety of learning support to these students. Based on the findings of a survey on "Supporting the learning of students with intellectual disabilities in mainstreaming schools", the presentation will include the analysis of the school support on curriculum arrangement, curriculum implementation, learning and teaching support, accommodation in examination and personal growth. The presentation will be concluded with recommendations and supporting strategies.

## 生命號，啟航吧！“Life Voyage” Let's Set Sail!

分享 Shared by  
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香港唐氏綜合症協會家長委員會主席  
Chairlady, Parents Committee, The Hong Kong Down Syndrome Association

楊女士將會向大家分享她與唐氏綜合症兒子的成長故事，如何協助兒子面對每天的挑戰，讓自己、兒子和家人活出精彩和不一樣的人生。

Ms. YEUNG will share her story about growing up with a son with Down Syndrome and her resilience of handling life challenges. Her story will bring the audience with different but positive life perspectives and illustrate how her family works out a rich and bright life.