



院長的話

籌劃逾十年，香港兒童醫院終於如期啟用。這也是我們的第一個聖誕節，感覺別具意義。開院當天，我在專科門診向病童送上義工製作的節日汽球，又看到他們與志願團隊玩得不捨得離開，彷彿忘記自己身處醫院。新聞報道傳來家長對我們設施和服務的正面評語，隔天又有醫生自發扮聖誕老人派禮物。這一幕幕溫馨畫面，令我既感動又感恩。

專科門診服務順利開始的同時，我亦要提醒市民，香港兒童醫院是負責診治嚴重複雜的個案，因此不設急症室或普通科門診。即是說，病人須按臨床情況經醫生轉介，再事先預約。如小朋友患上流感、腸胃炎等較輕微病症或不幸遇到意外，應到其他醫院或診所求醫；而開院頭數月我們只處理覆診舊症，直至今年住院服務陸續開展，有關專科才會接受新症轉介。

為了傳達這些重要訊息，我們會加強與公眾、服務使用者和醫療業界的溝通。其中各科的轉介指引會逐步上載醫院網站。我亦計劃開通網誌，與同事分享所想。

開院了!

we are open!



醫院的地址是「承昌道一號」，聽起來與「成長道」很相似。我一直希望我們能成為一間充滿關懷、學習精神和微笑的醫院。隨著臨床服務相繼開展，但願這些種子與我們的病童一起茁壯成長。

香港兒童醫院行政總監李子良醫生



Message from HCE

After over ten years of planning, we have finally opened our doors to patients just before Christmas. It was gratifying seeing the happy faces of children receiving festive balloons made by volunteers, doctor dressing up as Santa Claus and parents' positive comments in the news. My heart is filled with thankfulness.

While the specialist outpatient clinics have opened smoothly, it is important to highlight that there is no accident and

emergency department or general outpatient clinic in HKCH, as we are a tertiary hospital focusing on complex cases. Patients need doctor's referral to make an appointment, which means there is no walk-in. Children suffering from injuries or relatively minor illnesses such as flu and gastroenteritis should seek medical attention from other hospitals or clinics. In the initial months, HKCH only provides follow-up consultation for existing patients. New referrals will be accepted when the respective specialties begin their inpatient service by phases from 2019.

We will spread these messages to the public via various channels, like posting referral guidelines on our website. I also plan to start a blog to share my thoughts with colleagues.

As we embark on a new journey with more services to come, let's make a new year's resolution to build a caring, learning and smiling hospital together.

Dr Lee Tsz-leung, HKCH Hospital Chief Executive



專科門診服務啟用 Specialist outpatient service begins



專科門診迎接第一批病童前，九龍中聯網總監盧志遠醫生、醫院管治委員會主席李聯偉先生、醫院行政總監李子良醫生切蛋糕祝願一切順利
KCC Cluster Chief Executive Dr Albert Lo, HGC Chairman Mr John Lee and Hospital Chief Executive Dr Lee Tsz-leung wish the hospital a smooth opening before it welcomes the first batch of patients

度高磅重都要充滿活力
Striking a pose during examination



香港兒童醫院 2018 年 12 月 18 日正式啟用。其中腎科、血液及腫瘤科、先天性新陳代謝科的專科門診，與及病理科、放射科及藥劑部率先投入運作，為符合指定臨床情況的病童提供服務。

開院第一天有九名來自瑪嘉烈醫院兒童腎科的病童前來專科門診覆診。連同瑪麗醫院及威爾斯親王醫院兒童癌症中心轉介的舊症，暫時已有超過 260 名病童預約覆診。專科門診亦會跟進政府「初生嬰兒代謝病篩查計劃」下化驗結果異常的嬰兒。

醫院其他專科的門診及住院服務二〇一九年起陸續開展，包括腫瘤科、腎科、小兒外科、兒童深切治療部、新生兒深切治療部、心臟科及心胸外科。

The Hong Kong Children's Hospital officially commenced service on 18 December 2018. The specialist outpatient clinics for nephrology, oncology and metabolic medicine, as well as pathology, radiology and pharmacy departments have since begun operation to serve patients with specific clinical conditions.

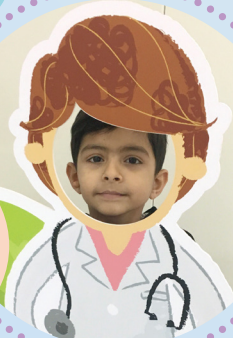
On the first day of service, nine patients originally under the care of Princess Margaret Hospital's paediatric nephrology team came to HKCH for follow-up consultation. In addition to the existing cases referred by the children's cancer centres of Queen Mary Hospital and Prince of Wales Hospital, more than 260 patients have booked their appointment at HKCH. The hospital will also follow up on babies identified with abnormal findings under the Government's newborn screening programme for inborn errors of metabolism.

Other outpatient clinics and inpatient services for oncology, nephrology, paediatric surgery as well as the paediatric intensive care unit, neonatal intensive care unit, cardiology and cardiothoracic surgery will be commissioned gradually in 2019.

義工團隊準備了遊戲和禮物，與病童慶祝聖誕
Volunteers bring holiday cheers to young patients with games and gifts



看完醫生，來扮演醫生吧
I want to be a doctor too



聖誕老人向病童大派禮物
Santa Claus comes to the clinic



醫院的設計很好。登記、見醫生、驗血、照超聲波和取藥在同一大樓的上下層，比較歸一方便。今日的流程很快速，醫護人員非常友善，等候期間又有圖書看。香港有這些設備應感到自豪。
It's convenient that everything is housed in the same building. We can complete registration, consultation, blood-taking, imaging and collect drugs without walking distances. The flow is quick and efficient, all the staff are very nice, and there are books to read. Hong Kong should feel proud to have such a facility.



盧醫生到抽血室為同事打氣
Dr Lo inspects the blood-taking room



他們的心聲 What we think

一級行政助理 Anita
Anita, Executive Assistant I

我負責在繳費處替病人登記。開院前我們演習了整個覆診流程，感恩首日運作十分順利。希望其他專科可盡快投入服務，令更多病童受惠。
I serve patients at the shroff and registration counter. I am so grateful that everything ran smooth on the first day. I hope other specialties could start service soon to benefit more patients.



註冊護士 Gigi
Gigi, Registered Nurse

我和一班同事努力多時，合力購置傢具、儀器以至玩具。看到門診終於啟用，令我十分感動。有家長甚至要求我們將其他專科的覆診期轉來兒童醫院呢。
I feel so touched seeing how our preparation and teamwork pay off. Some parents even asked to change their appointment under other specialties to HKCH.



抽血員 Cherrie
Cherrie, Phlebotomist

為了令抽血過程更流暢，我們為抽血室的桌椅和工具擺位作了一番調整，亦準備了貼紙及糖果，獎勵勇敢面對抽血的小朋友。
We spent quite some time planning the layout of our workstations to make it more user-friendly. We have also prepared some stickers and candies to award the brave kids.



這間醫院很漂亮，很舒服。
I feel comfortable in this pretty hospital.



第一名病人余日曦與母親
First patient Julian Yue and his mother

資訊科技助理 Vaiko & Jim
Vaiko & Jim, IT Assistants

我們為醫院裝設電腦及網絡系統，令臨床運作更智能化。看到自己的工作能夠幫助病童，感到很開心。
Through setting up computers and network systems, we help create a smart environment to enhance clinical workflow. It's blissful to see how our work indirectly helps the patients.



一站式服務 全面照顧代謝病童

One-stop service for children with IEM

上期《通訊》預告香港兒童醫院將支援全港「初生嬰兒代謝病篩查計劃」，其中化驗服務已於去年十月順利開展，成為醫院的先頭部隊，而新陳代謝科亦剛投入服務，跟進治療有關個案。另外，衛生署醫學遺傳科預計 2019 年底遷入。日後相關不常見疾病的檢測、診斷、治療及家庭輔導將集中在本院，為患者提供一站式支援，專家們亦可累積經驗，並為研究發展奠下基礎。

HKCH is responsible for the laboratory testing for the territory-wide newborn screening for inborn errors of metabolism (IEM), and providing treatment for relevant cases. The Department of Health's Clinical Genetic Service will also move into HKCH in late 2019. These prepare HKCH as a one-stop centre for related uncommon disorders where testing, diagnosis, treatment and counselling could be provided under one roof.

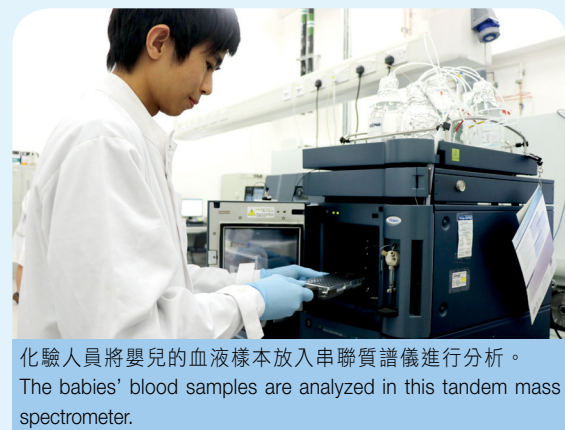
病理科：給嬰兒送上生日禮物

病理學部顧問醫生麥苗一直參與代謝病篩查的籌劃，包括將檢測儀器由瑪嘉烈醫院和仁濟醫院遷移至本院。她說：「這計劃是給嬰兒寶貴的生日禮物。無病固然是好消息，就算不幸確診，亦可立即展開治療。化驗只需幾滴血，但結果卻是天淵之別，足以改寫寶貴一生。」

她憶起自己很久以前在化驗室對著一份報告嘆息的往事：「當時我們驗出一名幼童患有苯丙酮尿症，但畢竟太遲發現，已經損害了智力而很難挽回，很心痛。」苯丙酮尿症正是現時篩查計劃涵蓋的 24 種代謝病之一，只要及早給予藥物及營養治療，就能減低對身體器官的破壞。「對社會來說，這些病或者屬於罕見；但對於家庭來說，每個小孩都是他們的全部。」



在這小小的化驗室裡，麥苗醫生（前排中）和團隊默默為初生嬰兒預備「生日禮物」——檢驗他們有沒有先天性代謝病。
This humble lab is where Dr Chloe Mak (middle in front row) and her team prepare “birthday gifts” for the newborn babies by testing whether they have IEM.



化驗人員將嬰兒的血液樣本放入串聯質譜儀進行分析。
The babies' blood samples are analyzed in this tandem mass spectrometer.

Pathology – giving babies a gift of life

Dr Chloe Mak, Consultant (Pathology) has been involved in the planning of the screening programme since its pilot. She described it as a precious birthday gift for newborn babies, “It’s certainly good news if the result comes out fine. Even if it is positive, treatment can begin right away. We only need a few drops of blood for the test but it can change the baby’s life.”

Dr Mak recalled that she was upset in the lab after reading the report of a phenylketonuria (PKU) case. “I felt so sorry for the kid. The intellectual development had already been damaged and nothing could be done to reverse it completely.” PKU is now included as one of the 24 IEM in the screening programme. It can be treated with medications and dietary therapy at an early stage to prevent mental retardation. She added, “For the society, these diseases may be uncommon; but for a family, every single child is everything.”

醫學遺傳科：解謎人與輔導員的雙重身份

衛生署醫學遺傳科預計今年底遷入本院，包括人手、儀器與病人。其顧問醫生盧輝文相信，與醫管局的專家們「同一屋簷下」有利雙方溝通，屆時個案轉介會更直接，衛生署亦可為住院病人提供即時會診。

遺傳科的工作包括檢驗及診斷遺傳病，過程有如偵探追兇。盧醫生說：「面對那些連我自己都未遇過的病，該如何診斷？這是一種藝術。」人體有二萬多個遺傳基因，其中三至四千個與已知的疾病相關。一般進行臨床評估後，會透過染色體分析和基因檢測等技術作診斷。對於毫無頭緒的個案，甚至要進行全基因組測序。

盧醫生當初誤打誤撞下進入冷門的遺傳科，一做便是廿多年，幫助了不少家庭。他說：「雖然大部份遺傳病不能根治，但對於那些看了多年醫生都找不到答案的人，能得到正確診斷會有一種如釋重負的感覺，不用再猜度自己究竟做錯了甚麼，會否牽連其他家庭成員等。」

遺傳科亦負責提供輔導，醫生會向患者解釋疾病成因、遺傳模式、患病機率及如何預防延至下一代等，讓他們作出更合適的生育計劃。盧醫生認為遺傳輔導的挑戰性不比遺傳診斷小：「要因應求診者的背景、教育程度、對疾病的掌握、當時的精神狀態和心情去耐心講解。」

新陳代謝科：與超人父母同行

篩查計劃下化驗結果異常的嬰兒，不論在哪間醫院出生，都會交由本院先天性新陳代謝科跟進。團隊由兒科醫生、專科護士及營養師組成。負責領導的許鍾妮醫生說：「當家長知道子女患有代謝病都會大受打擊。照顧這些小朋友要承受巨大壓力，所以他們都是超人父母。我希望告訴他們，醫護人員會與他們同行，盡力給予最好的治療。」

許醫生認為，每種罕有病的第一名病人都是醫生的老師，教懂他們如何治理將來的患者。以往這些個案分散在不同醫院，數量又少，再遇到相同病例可能是十年後的事。「我等了二十多年，終於見到這些病集中在同一間醫院治療，可以累積經驗和最新知識，對醫生和病人都是好事。」是否美夢成真？她說：「兒童醫院是夢工場，現在踏出了第一步，尚有許多未發完的夢。」



許鍾妮醫生（右三）的跨專業團隊是代謝病小朋友和家庭的重要伙伴，在治療路上同行。
Dr Joannie Hui (third from right) and her team are close partners with IEM patients and families during their treatment journey.



Clinical Genetic Service - from solving riddles to counselling

The Clinical Genetic Service of the Department of Health is scheduled to relocate to HKCH in late 2019. Consultant Clinical Geneticist Dr Ivan Lo believes this would facilitate their communication with specialists of the Hospital Authority. Patient referral would be more direct and they could provide inpatient consultation more easily.

While conducting investigation and making diagnosis of genetic diseases are the team's daily routine, the process is by no means straightforward. Dr Lo said, “It’s like solving puzzles. How to diagnose a disease that I have never encountered before? This is quite an art.” There are 3,000 to 4,000 known genetic diseases. Different genetic technologies are used to tell what is actually wrong with a patient. For very difficult cases, whole exome/genome sequencing may be required.

Dr Lo has helped many families over the past twenty years. “Although most genetic diseases are incurable, having a definite diagnosis can be a relief to patients who have been seeing different doctors for years to no avail.”

Counselling is another service provided by the team, which involves explaining the mode of inheritance, risk of occurrence and how to prevent passing the disease to the next generation in order to help clients with their family planning. “We have to assess the clients’ background, educational level, knowledge of the disease and mental state when offering counselling.”



盧輝文醫生抽絲剝繭，透過各種遺傳檢測技術為求診者找出病因。
With the help of different genetic technologies, Dr Ivan Lo has solved many puzzles to give his patients a long-awaited answer.



香港兒童醫院位處九龍城區的啟德，亦鄰近觀塘及黃大仙。三區的議員及民政事務專員前來了解醫院服務、設施及交通配套。
Members of the Kowloon City, Kwun Tong and Wong Tai Sin District Councils are interested to know about the hospital services, facilities and transport accessibility.



傷健團體「栢力與確志」視察後，對各項無障礙設計表示滿意，亦提出了一些改善建議，令設施更切合使用者需要。
The Paraplegic & Quadriplegic Association inspect the barrier-free access and facilities.



與兒童癌病基金交流意見。
Exchanging views with the Children's Cancer Foundation.



兒童心臟基金會參觀日後病童接受治療的心臟科中心。
The Children's Heart Foundation visits the Cardiology Centre.



理工大學醫療及社會科學院到訪，了解專職醫療及護理服務的提供情況。
Professors of the Polytechnic University's Faculty of Health and Social Sciences learn about the provision of allied health and nursing services in HKCH.

實地視察 促進交流 Site visits to foster exchange



米奇醫生和米妮護士與醫管局總部、九龍中聯網及香港兒童醫院同事一起出席「童康服」項目公布儀式
Dr Mickey and Nurse Minnie with Hospital Authority Head Office, Kowloon Central Cluster and HKCH colleagues at the launching ceremony of the Dress Well project

童康服為病童 送上祝福

香港兒童醫院一直希望通過不同方法，為小朋友帶來不一樣的治療體驗，令他們感受到關懷和希望。其中，我們與香港迪士尼樂園團隊花了不少心思，合力為病童創作了一系列集美觀、舒適及實用功能於一身的特色住院服裝，包括睡衣套裝、外套，及接受靜脈注射時穿著的上衣。華特迪士尼公司同時慷慨捐贈 410 萬元，支持這批服裝的製作費用。

項目以「童康服」為名，寓意這些色彩繽紛的服裝為病童的住院歷程注入歡樂，令他們更輕鬆面對治療，踏上康復之路。

隨著住院服務今年起陸續開展，病童便可穿上這些設計貼心的全新服裝了。

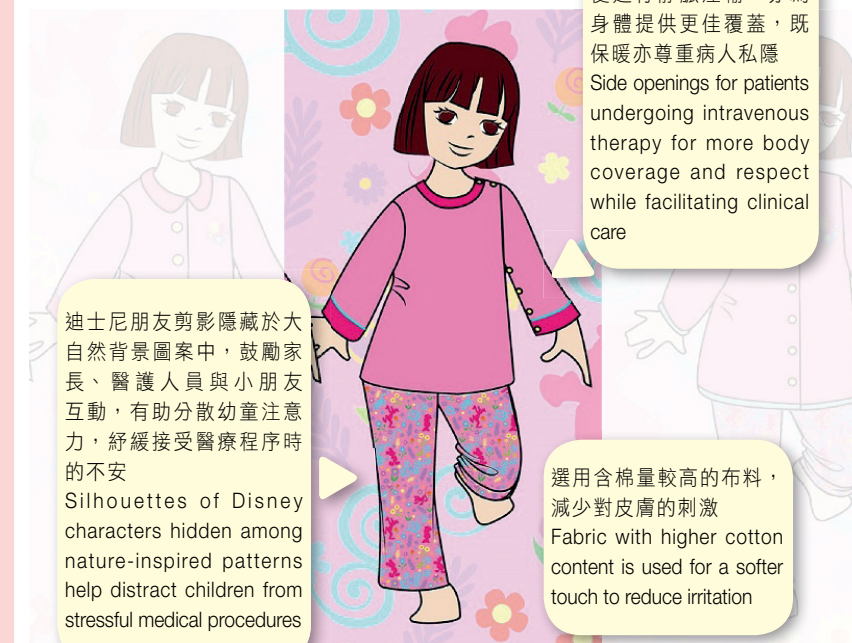
New inpatient clothing specially designed for children

The HKCH has always been looking for ways to bring child patients a better treatment experience filled with love. To this end, we have partnered with the Hong Kong Disneyland Resort to create a series of new inpatient clothing which combine visual appeal, comfort and functionality. These include regular pyjamas, jackets, and pyjama tops for intravenous therapy. A generous donation of \$4.1 million was also received from the Walt Disney Company to support the production cost.

It is hoped that the colourful clothing under this "Dress Well" project would inject doses of happiness and accompany the children throughout their hospital journey.

These unique clothing will be available for child patients when inpatient services commence gradually from this year.

住院服設計解構 Design highlights



醫院遇襲？ HKCH joins police exercise

警方早前動員 150 人在香港兒童醫院舉行演習，以加強雙方在緊急事故中的協調及應變能力。演習代號「壯志」，模擬醫院保安員於大堂發現數名可疑人物報警，東九龍衝鋒隊奉召到場。匪徒其後開火並挾持人質，警方隨即調派機動部隊、反恐特勤隊及談判組增援，並封鎖現場搜索及疏散市民，最終將匪徒制服。

The Police conducted a 150-people exercise in the hospital premises earlier with an aim to enhance coordination and response during emergency situations. Codenamed "Aim High", the drill began with a hospital security staff spotting some suspicious persons in the lobby and the Kowloon East Emergency Unit soon arrived at the scene. The criminals then opened fire and seized a hostage. The Police Tactical Unit, Counter Terrorism Response Unit and Police Negotiation Cadre were deployed immediately to lock down the area and evacuate the civilians. The criminals were taken down eventually.



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獲臨時認證為兒科醫生培訓單位

Provisional accreditation of HKCH as training centre for paediatricians

香港兒童醫院獲香港兒科醫學院發出臨時認證，批准其心臟科、腎科、血液及腫瘤科、兒童深切治療部，及新生兒深切治療部成為兒科專科受訓醫生的培訓單位。

HKCH has obtained provisional accreditation from the Hong Kong College of Paediatricians for five units, namely Cardiology, Nephrology, Haematology / Oncology, PICU and NICU as training units under the General Paediatrics Specialist Training Programme.

- Basic Trainees would be accredited for three months (but no more than 6 months) in each subspecialty
- NICU training will be recognized for three months Basic training but this will not be counted as part of the six months general neonatology training required (i.e. as elective training)
- Higher trainees would be accredited for training in each subspecialty and the maximal training is 12 months in all the subspecialties except NICU which is recognized for maximum of 6 months only

