立法會
Legislative Council

LC Paper No. CB(2)292/17-18
(These minutes have been seen by the Administration)

Ref : CB2/PL/HS

Panel on Health Services

Minutes of special meeting
held on Tuesday, 11 April 2017, at 10:00 am
in Conference Room 1 of the Legislative Council Complex

Members present	:	Prof Hon Joseph LEE Kok-long, SBS, JP (Chairman) Dr Hon Pierre CHAN (Deputy Chairman) Hon CHAN Kin-por, BBS, JP Hon Mrs Regina IP LAU Suk-yee, GBS, JP Hon Paul TSE Wai-chun, JP Hon LEUNG Kwok-hung Hon YIU Si-wing, BBS Hon Charles Peter MOK, JP Hon CHAN Chi-chuen Hon CHAN Han-pan, JP Dr Hon KWOK Ka-ki Dr Hon Fernando CHEUNG Chiu-hung Hon POON Siu-ping, BBS, MH Hon CHU Hoi-dick Hon SHIU Ka-fai Hon YUNG Hoi-yan Hon Jeremy TAM Man-ho
Member attending	:	Hon LAM Cheuk-ting
Members absent	:	Hon Tommy CHEUNG Yu-yan, GBS, JP Hon WONG Ting-kwong, SBS, JP Hon Alice MAK Mei-kuen, BBS, JP Dr Hon Helena WONG Pik-wan Dr Hon Elizabeth QUAT, JP Dr Hon Junius HO Kwan-yiu, JP Hon SHIU Ka-chun

[According to the Judgment of the Court of First Instance of the High Court on 14 July 2017, LEUNG Kwok-hung, Nathan LAW Kwun-chung, YIU Chung-yim and LAU Siu-lai have been disqualified from assuming the office of a member of the Legislative Council, and have vacated the same since 12 October 2016, and are not entitled to act as a member of the Legislative Council.]

Public Officers attending :

Prof Sophia CHAN Siu-chee, JP
Under Secretary for Food and Health

Ms Grace KEI
Acting Principal Assistant Secretary for Food and Health (Health) 2
Food and Health Bureau

Dr CHEUNG Wai-lun
Director (Cluster Services)
Hospital Authority

Ms Anna LEE
Chief Pharmacist
Hospital Authority

Mr Daniel LO
Senior Manager (Allied Health)
Hospital Authority

Attendance by invitation :

Hong Kong Ample Love Society Ltd.

Ms TSANG Cheuk-yi
Chairlady

The Civic Party

Mr LEE Ka-ho
Representative

Democratic Alliance for the Betterment and Progress of Hong Kong

Miss CHEUNG Ip-mei
Community Officer

Ms CHAN Wai-chun

Ms Tara Wanye Sam

PNH 病人權益關注組

Mr CHAN Kim-tong
Representative

Miss CHAN Wai-sze

Ms WONG Fung-ming

Tuberous Sclerosis Complex Association of Hong Kong

Ms Rebecca YUEN Pui-ling
President

Ms HUI Ching-yee

Ms Grace WONG Ching-yuen

Dr CHUNG Hon-yin

Hong Kong Alliance for Rare Diseases

Mr TSANG Kin-ping
President

Mr LAI Ka-wai

Ms LI Shui-yin

Ms CHI Yin-lan

Miss NG Hei-tung

Mr FONG Chi-wai

Clerk in attendance	**:**	Ms Maisie LAM Chief Council Secretary (2) 5
Staff in attendance	**:**	Ms Ivy CHENG Senior Council Researcher 3

Miss Kay CHU
Senior Council Secretary (2) 5

Ms Priscilla LAU
Council Secretary (2) 5

Miss Maggie CHIU
Legislative Assistant (2) 5

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I. Policy on and drugs for rare diseases
[LC Paper Nos. CB(2)979/16-17(06) to (07), CB(2)1022/16-17(11) and IN07/16-17]

Presentation of views by deputations

Members noted the following papers on the subject under discussion:

(a) the paper provided by the Administration (LC Paper No. CB(2)979/16-17(06));

(b) information note on rare disease policies in selected places prepared by the Research Office of the Information Services Division of the Legislative Council ("LegCo") Secretariat (IN07/16-17); and

(c) the background brief entitled "Policy on and drugs for rare diseases" prepared by the LegCo Secretariat (LC Paper No. CB(2)979/16-17(07)).

2. The Chairman reminded the organizations and individuals attending the meeting that they were not covered by the protection and immunity provided under the Legislative Council (Powers and Privileges) Ordinance (Cap. 382) when addressing the Panel. At the invitation of the Chairman, a total of 18 organizations and individuals presented their views on the policy on and drugs for rare diseases. A summary of their views is in the **Appendix**. Members also noted four written submissions from individuals not attending the meeting.

Discussion

Drug subsidy programmes

3. Mr LAM Cheuk-ting was of the view that given the huge fiscal surplus of the Government, no patients suffering from rare diseases should be denied necessary drug treatment due to lack of means. While the

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proposal of the Hospital Authority ("HA") to firstly include Eculizumab, the drug for treating Paroxysmal Nocturnal Haemoglobinuria ("PNH"), in the proposed assistance programme for ultra-expensive drugs under the Community Care Fund ("the proposed CCF programme") could be regarded as a step forward in this regard, he was gravely concerned that the patient's maximum contribution to drug expenses would be either 20% of the annual disposal household financial resources of the family or $1 million, whichever was the lower. He considered the threshold too high that the families concerned would deplete their financial resources in just a few years. The Administration should instead highly subsidize all patients with rare diseases to support their ultra-expensive drug treatment such that their quality of life would not be deteriorated significantly.

4. Under Secretary for Food and Health ("USFH") explained that the proposed CCF programme was aimed at filling the gaps in the existing drug subsidy mechanism which was kept under review and creating a pioneering effect. Director (Cluster Services), HA ("D(CS), HA") advised that HA needed time to study whether the Samaritan Fund ("SF") was suitable to subsidize the relevant drugs for treatment of uncommon disorders. The implementation of the proposed CCF programme, which was targeted to be opened for application in August 2017 if endorsed by the Commission on Poverty, would enable early use of ultra-expensive drugs by needy patients and shed light on the feasibility of introducing ultra-expensive drugs into the safety net of SF or other funds. HA would revert to the Panel on the initial and final outcomes of the study, which would take time to complete, as and when appropriate.

5. Dr Fernando CHEUNG declared that he had a daughter who suffered from Mowat-Wilson Syndrome, a rare disease with no drug treatment available at this stage. Referring to the proposal to include Eculizumab in the proposed CCF programme for treating PNH, he asked whether patients with atypical haemolytic uremic syndrome ("aHUS") could apply for using Eculizumab for treating their disease. D(CS), HA responded that HA had looked into the issue. However, there was currently no established clinical studies and international guideline on dosing and uses of Eculizumab in this regard. Subject to the availability of such information, HA would consider including also the indication for the treatment of aHUS.

6. Mr LAM Cheuk-ting considered that current household-based financial assessment of various drug subsidy programmes, which in turn forced many patients concerned to separate from their core family members living under the same roof in order to meet the financial assessment criteria, was inhuman. Referring to the financial assessment criteria of the proposed

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CCF programme as set out in the Annex to the Administration's paper, he asked about whether all family members living under the same roof with the patients would be regarded as the patients' household. Dr KWOK Ka-ki held the view that the financial assessment of SF was too stringent that many families of cancer patients, chronic disease patients and rare disease patients had to deplete all their financial resources to purchase the self-financed drugs concerned at their own expense before becoming eligible for assistance.

7. D(CS), HA and Senior Manager (Allied Health), HA advised that the policy objective of various non-contributory financial assistance funded by general revenue was that members of a family living under the same roof should support each other. In response to the comments received from members and patients, HA had recently conducted a review of the household definition adopted in the financial assessments of the medical fee waiver mechanism, SF and CCF's medical assistance programmes. Under the refined definition to be adopted in the second half of 2017, household included only the core family members living with the patient, which might include the patient's spouse, children, parents and dependent siblings. Mr Jeremy TAM was of the view that the refined household definition should not cover all core family members living with the patient concerned. He enquired about whether household size would be a factor to be taken into account in calculating the annual disposable financial resources under the proposed CCF programme, which would in turn determine a patient's maximum contribution to the drug expense. Replying in the positive, D(CS), HA said that the respective amount of the total personal allowances and the deductible allowance would depend on the patient's household size.

HA Drug Formulary

8. In response to Mr LEUNG Kwok-hung's enquiry, D(CS), HA advised that under the HA Drug Formulary ("the Drug Formulary"), drugs were categorized into four groups, namely General Drugs, Special Drugs, Self-financed Items ("SFIs") with safety net and SFIs without safety net. General Drugs were drugs with well-established indications and cost-effectiveness which were available for general use as indicated by the patients' clinical conditions. Special Drugs were drugs used under specific clinical conditions with specific specialist authorization. The above drugs were provided at standard fees and charges in HA hospitals and clinics. SFIs with safety net were drugs which were proven to be of significant clinical benefits but were very expensive for HA to provide as part of its standard services. Patients who required these drugs had to purchase the drugs at their own expense. A safety net was provided to subsidize the

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drug expenses of needy patients. SFIs without safety net included drugs with preliminary medical evidence only or marginal benefits over available alternatives but at significant higher costs, and lifestyle drugs. They were not provided as part of HA's standard services nor covered by the standard fees and charges in HA hospitals and clinics. Patients who chose to use these drugs had to purchase them at their own expense.

9. The Chairman sought clarification from HA as to whether there were experts in the field of rare diseases to evaluate the relevant new drug applications for listing on the Drug Formulary, and whether the treatment costs of drugs for rare diseases, which were often ultra-expensive, were a factor to be taken into account in the evaluation. Dr KWOK Ka-ki surmised that the cost of a new drug was a major factor that the Drug Advisory Committee ("DAC") of HA would consider when evaluating an application for listing on the Drug Formulary. He suggested that DAC should comprise more persons outside HA to enhance its transparency and meet more frequently in view of the rapid development of pharmaceutical technology. Mr SHIU Ka-fai asked whether cost-effectiveness, if not the cost, of a new drug was a factor to be taken into account by HA under the existing mechanism.

10. D(CS), HA advised that DAC, which was tasked to evaluate new drugs for listing on the Drug Formulary, was supported by multiple expert panels in different specialty areas. The major issue of concern for using new drugs for clinical intervention was efficacy. If a drug satisfied the criteria for listing on the Drug Formulary as part of HA's standard services or as a SFI with safety net, HA would, where necessary, enlist additional provision from the Administration. At the request of the Chairman, D(CS), HA undertook to provide information on the amount of resources allocated by the Administration to HA in the past two years for provision of drugs for treatment of uncommon disorders based on the examination of the relevant independent expert panels.

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11. Mr LEUNG Kwok-hung considered that the absence of a rare disease policy and the guiding principle of the Drug Formulary that the finite public resources should be used to maximize the effects of healthcare and provide equitable access for all patients had the effect of upholding the interests of the majority of patients at the expense of the interests of those patients whose drug treatments were considered too expensive for HA to provide as part of its standard services. Expressing disagreement to the above view, USFH stressed that the provision of drugs for patients of HA was based on clinical conditions of patients under the treatment protocols.

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Rare disease policy

12. Stressing that lives were priceless, Dr Fernando CHEUNG expressed his intention to move a motion urging the Government to formulate a policy of, and set up a drug subsidy fund for rare diseases, the wording of which had been tabled at the meeting. Mr LAM Cheuk-ting said that he supported the proposals of Dr Fernando CHEUNG. Whilst expressing appreciation for the proposed CCF programme, Mr CHAN Han-pan said that he had repeatedly called for the formulation of a policy or legislative framework for the screening and treatment of rare diseases, which would cover the provision of prenatal screening, setting up of a database and developing a separate drug formulary for rare diseases. The above was not uncommon practices in the neighbouring places outside Hong Kong. He added that the provision of appropriate drug treatments for patients with rare diseases, which might involve a substantial amount of public resources, could in turn help relieve these patients' need for admission and hence, partly reduce the burden of public healthcare system.

13. Dr KWOK Ka-ki urged the Administration to formulate a rare disease policy, or at the very least allocate a dedicated provision to HA to provide subsidized drug treatments for rare disease patients. Mr Jeremy TAM held the view that in a buoyant society like Hong Kong, no rare disease patients should be prevented from obtaining appropriate drug treatments due to lack of means. While he had invited the Administration to earmark a provision for fully subsidizing drug treatments for needy patients suffering from rare diseases which, in his view, would not receive any objecting views from LegCo Members, the Administration and HA had only time and again stressed that the provision of drugs had to be based on the scientific and clinical evidence. Expressing support to Dr Fernando CHEUNG's motion, Mr SHIU Ka-fai asked about the estimated provision required for fully subsidizing drug treatments for needy rare disease patients. Noting that the revised fiscal surplus for the 2016-2017 financial year amounted to $92.8 billion, Mr CHAN Chi-chuen opined that the Food and Health Bureau should fight for additional resources, say $500 million, to provide drug subsidies for patients suffering from rare diseases.

14. USFH assured members that the Administration would look into ways to further improve the existing system in the light of the views expressed by members and deputations. That said, it should be noted that there was no internationally agreed definition of rare diseases. The definition varied among countries or regions depending on their own healthcare system and situation. D(CS), HA advised that in considering

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whether a policy or legislative framework should be formulated on uncommon disorders, due regard should be given to the fact that public healthcare services were currently provided at highly subsidized rates for local residents, and that each patient seeking consultation at public hospitals and clinics, regardless of whether they were suffering from uncommon disorders or not, would have equal access to appropriate treatment based on their clinical conditions and the treatment guidelines. D(CS), HA further advised that since HA had not defined rare diseases, he could not provide an estimation on the drug expenditure involved in this regard. Mr SHIU Ka-fai called on the Administration and HA to set up a database on rare diseases such that an estimated drug expenditure could be worked out to facilitate consideration on the way forward. Mr LEUNG Kwok-hung criticized the Administration for being reluctant to put in place a definition of rare diseases, albeit that the Mainland and many places outside Hong Kong had been doing so.

15. Dr KWOK Ka-ki reiterated that the Administration should allocate a dedicated provision to HA to provide subsidized drug treatments for rare disease patients. According to his understanding, it was not uncommon that individual specialties of public hospitals currently were not willing to take care of patients with suspected rare diseases as the annual recurrent funding allocated to them was unable to meet the expenditure for the ultra-expensive drug treatments required of by these patients. Hence, many patients suffering from rare diseases were forced to seek treatments from different specialties. D(CS), HA stressed that it was incumbent upon all healthcare professionals to ensure that each patient would receive appropriate medical care and drug treatments. It should also be noted that the Administration had allocated an additional annual recurrent funding amounting to $75 million to HA in phases to meet the increasing demand for ultra-expensive drug treatments for lysosomol storage disorders.

16. In response to Mr POON Siu-ping's enquiry, D(CS), HA advised that with the additional funding referred to in paragraph 15 above, HA had provided enzyme replacement therapy ("ERT") for patients with six types of lysosomol storage disorders ("LSD"), namely Pompe, Gaucher, Fabry and Mucopolysaccharidosis ("MPS") Types I, II and VI, through the assessment of an independent expert panel. At present, 22 patients with LSD were undergoing ERT in public hospitals. The annual cost in this regard was around $60 million. These patients would be assessed by the expert panel every year. At the request of the Chairman, USFH undertook to provide information on the annual drug expenditure of HA for treatment of patients with uncommon disorders and the number of patients involved.

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Diagnosis of and drug treatments for rare diseases

17. Dr Fernando CHEUNG invited the views of Dr CHUNG Hoi-yin on the existing arrangement that there was no specialty of clinical genetics for diagnosis and management of rare diseases in public hospitals and clinics. Dr CHUNG Hoi-yin said that many rare diseases were rooted from genetic problems. The absence of a specialty of clinical genetics in HA had made it difficult to attract talents to pursue a career in this regard. Separately, the types of inborn errors of metabolism ("IEM") covered under the Pilot Study on Newborn Screening for IEM currently implemented in two birthing public hospitals only accounted for a small proportion of rare diseases. In response to the Chairman's enquiry on the provision of relevant specialist training in Hong Kong, Dr CHUNG Hoi-yan said that an application for accreditation of the subspecialty of paediatric endocrinology and metabolic medicine had been submitted to the Hong Kong College of Paediatricians under the Hong Kong Academy of Medicine. Hence, it was an opportune time for HA to consider whether a corresponding medical grade should be established in public hospitals.

18. USFH and D(CS), HA advised that the newly developed Hong Kong Children's Hospital, which would commence operation by phases in 2018, would serve as a tertiary referral centre for complex and rare paediatric cases which required multi-disciplinary management. It was planned that clinical genetics services would be provided at the Hospital, which would mark a milestone for the development of Hong Kong in this regard. D(CS), HA added that the screening service for IEM would be extended to all public hospitals with maternity wards in phases from the second half of 2017-2018.

19. Dr KWOK Ka-ki remarked that gene sequencing could improve diagnoses for patients with rare diseases. At the invitation of Dr Fernando CHEUNG, Ms Grace WONG said that the experience of her son suggested that gene sequencing could help diagnose rare diseases more accurately as many rare diseases had a genetic component. This would in turn facilitate the provision of correct drug treatments. She further remarked that given the small number of patients suffering from each rare disease, it was inappropriate to determine drug management on the basis of clinical evidence. In addition, the use of public resources to support treatments of patients should not induce confrontation between patients suffering from rare diseases and patients suffering from common diseases. At the invitation of the Chairman, Dr CHUNG Hoi-yin echoed the view of Ms Grace WONG that it would be difficult to apply the principle of evidence-based medicine on drug treatments for rare diseases patients, in

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particular those patients in their childhood, as the number of patients was limited and clinical trials were seldom conducted on children.

[At this juncture, the Chairman informed members of his decision to extend the meeting for 15 minutes beyond its appointed ending time to allow more time for discussion. At the suggestion of the Chairman, members agreed that the motion proposed by Dr Fernando CHEUNG, which were directly related to the agenda item under discussion, would be dealt with towards the end of the discussion.]

20. Mr CHAN Chi-chuen expressed concern that there were cases whereby the provision of subsidized drug treatments for some individual patients was terminated upon review as the conditions of the patients concerned changed when undergoing the treatments. Hence, the patients concerned had to resort to other means in order to continue the drug treatments which were extremely expensive. Mr LEUNG Kwok-hung asked whether the cost of the drug treatment was a factor causing the termination of the treatment. D(CS), HA clarified that clinical decisions made by the attending doctors and the expert panels concerned on the initiation, continuation and termination of a drug treatment for a patient were solely based on whether the treatment was proven to be of clinical benefits to the patient concerned according to the relevant treatment protocol.

21. Dr Fernando CHEUNG urged HA to provide the ultra-expensive drugs for treating MPS Type IV and tuberous sclerosis complex ("TSC") at standard fees and charges. He was particularly concerned about the drug treatment for a six-year-old child who was suffering from MPS Type IV A.

22. D(CS), HA explained that the use of a drug treatment for patients would depend on, among others, the safety and efficacy of the drug and clinical conditions of individual patients. In addition, pharmaceutical companies, which set the price of the drugs, played a crucial role in determining the sustainability of the long-term treatment for uncommon disorders. As regards the provision of ERT for the child referred to by Dr Fernando CHEUNG, HA was liaising with the pharmaceutical company concerned on the feasibility of offering a compassionate long-term drug arrangement given the proved clinical benefit of the drug therapy to the patient. This was not an uncommon practice of pharmaceutical companies worldwide. D(CS), HA further advised that while TSC could not be cured, there were different approaches to treat or manage some of the associated symptoms. A self-financed drug for treating TSC with subependymal giant cell astrocytoma would be included in SF in July 2017. At present, approaches to manage those tumours developed in other vital organs

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included surgical removal and interventional treatment. The relevant expert panel had been requested to formulate the treatment protocols in this regard. Subject to the outcome of discussion of the expert panel, HA would further expand the coverage of SF to benefit more patients with TSC.

23. Mr Jeremy TAM said that to his understanding, many international pharmaceutical companies had derived hefty profits from their business. However, the exorbitant prices charged by these companies for drugs for treating rare diseases, which might cost several million dollars a year, had made the drugs unaffordable to average patients on the one hand, and on the other hand made it impracticable for HA to include the drugs in its subsidized services. Given that Hong Kong was considered a small market, he suggested that the Administration could explore with the relevant Mainland authorities the feasibility of placing the drug orders along with that of the Mainland, or making Hong Kong a testing ground for drugs entering into the Mainland market so as to increase the negotiating power of Hong Kong. In addition, an alliance of rare disease patients and LegCo Members could be formed to urge the pharmaceutical companies concerned to lower their drug prices and offer more trial therapies for suitable needy patients. D(CS), HA advised that efforts had been and would continuously be made by HA to discuss with the pharmaceutical companies concerned on the offering of compassionate drug treatment for individual patients. He agreed that patients and LegCo Members had a role to play in this regard.

24. Referring to a case whereby a patient suffering from spinal muscular atrophy intended to use a drug not registered in Hong Kong, Mr SHIU Ka-fai asked about the mechanism for importing an unregistered drug for the purpose of treatment. D(CS), HA advised that any importation of an unregistered drug for the purpose of treatment of a particular patient by a registered medical practitioner would be considered by the Department of Health on a case by case basis. Mr SHIU Ka-fai said that he would follow up the case with the Administration after the meeting.

Motion

25. The Chairman invited members to consider whether the motion proposed by Dr Fernando CHEUNG should be proceeded with at this meeting. Members raised no objection. The Chairman ordered that the voting bell be rung for five minutes to notify Panel members of the voting.

26. Dr Fernando CHEUNG moved the following motion:

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"香港沒有就罕見病作出定義，也沒有全面數據庫，沒有政策，沒有立法，病人往往面對診斷遲，藥費昂貴以至超乎一般人的負擔能力，缺乏支援等。本委員會促請政府立即訂立罕見病政策，成立跨部門罕見病中央管理委員會，就預防、診斷、治療、藥物、專科人手培訓、支援、立法等訂下政策及推行框架，並應立即增撥 5 億元，設立罕見病藥物資助基金，為罕見病病人提供藥物資助。"

(Translation)

"Currently, there is no definition of or comprehensive database on rare diseases in Hong Kong. There is also no corresponding policy and legislation, and patients are often plagued by the problems of late diagnosis, expensive drug costs that go beyond the affordability of the general public, lack of support, etc. This Panel urges the Government to immediately formulate a policy on rare diseases, and establish an inter-departmental central committee on management of rare diseases to formulate a policy on and an implementation framework for prevention, diagnosis, treatment, medications, specialist training, provision of support, legislation, etc. The Government should also immediately earmark $500 million to set up a rare diseases drug subsidy fund to provide drug subsidies for patients suffering from rare diseases."

27. The Chairman put the motion to vote. All 11 members present at the meeting voted for the motion unanimously. The Chairman declared that the motion was carried.

Way forward

Research Office, LegCo Secretariat

28. Mr CHAN Han-pan proposed that the Panel should conduct an overseas duty visit to study rare disease policies. The Chairman requested the Research Office of the Information Services Division of the LegCo Secretariat to prepare some supplementary information on rare disease policies in selected places to facilitate members' consideration of the proposal. The Chairman suggested and members agreed that subject to the time required by the Research Office of the LegCo Secretariat to complete the study, the Panel would consider whether to conduct the proposed duty visit at its May regular meeting. In the case that the Panel considered it necessary to conduct the subject duty visit, prior permission of the House Committee would be sought. Against the above, the earliest time for conducting the duty visit would be after the summer recess.

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29. In closing, the Chairman called on the Administration and HA to take heed of the views expressed by members and deputations, which included, among others, the need to formulate a definition of and a database for rare diseases, establish a clinical genetics specialty in HA, address the gaps in the existing mechanisms in relation to the provision of subsidized drug treatments for rare disease patients, and put more efforts in negotiating with the pharmaceutical companies concerned with a view to lowering the relevant drug prices and offering more compassionate drug treatments for individual patients.

II. Any other business

30. There being no other business, the meeting ended at 12:37 pm.

Council Business Division 2
Legislative Council Secretariat
13 November 2017

Appendix

Panel on Health Services

Special meeting on Tuesday, 11 April 2017, at 10:00 am in Conference Room 1 of the Legislative Council Complex

Summary of views and concerns expressed by organizations/individuals on policy on and drugs for rare diseases

No.	Name of deputation/individual	Submission / Major views and concerns
1.	Hong Kong Ample Love Society Ltd.	• The Liberal Party had called on the Administration to approve applications for the Samaritan Fund ("SF") in a lenient approach and enhance SF by injecting an additional $1 billion, expanding its coverage and relaxing the eligibility criteria since the 2012-2013 financial year. • Many new and ultra-expensive drugs were not provided for patients at standard fees and charges, leaving some chronically ill patients being denied of adequate medical treatments due to lack of means.
2.	The Civic Party	• LC Paper No. CB(2)1214/16-17(01)
3.	Democratic Alliance for the Betterment and Progress of Hong Kong	• To strengthen the support and care for patients with rare diseases, the Administration should allocate more resources to subsidize their heavy medical expenses, make reference to relevant practices in other places to establish a definition of rare diseases and set up a database on rare diseases.
4.	Ms CHAN Wai-chun	• The Drug Formulary of the Hospital Authority should be expanded so that more drugs for treating rare diseases could be provided for needy patients at standard fees and charges. • A database on rare diseases should be set up and frontline medical professionals' knowledge of rare diseases should be strengthened.
5.	Ms Tara Wanye Sam	• LC Paper No. CB(2)1128/16-17(01)
6.	PNH 病人權益關注組	• LC Paper No. CB(2)1128/16-17(02)
7.	Miss CHAN Wai-sze	• LC Paper No. CB(2)1128/16-17(03)
8.	Ms WONG Fung-ming	• LC Paper No. CB(2)1128/16-17(04)
9.	Tuberous Sclerosis Complex Association of Hong Kong	• LC Paper No. CB(2)1128/16-17(04) • LC Paper No. CB(2)1326/16-17(01)
10.	Ms HUI Ching-yee	• LC Paper No. CB(2)1214/16-17(02)
11.	Ms Grace WONG Ching-yuen	• LC Paper No. CB(2)1128/16-17(06)
12.	Dr CHUNG Hon-yin	• LC Paper No. CB(2)1128/16-17(07)

No.	Name of deputation/individual	Submission / Major views and concerns
13.	Hong Kong Alliance for Rare Diseases	• LC Paper No. CB(2)1128/16-17(07) • LC Paper No. CB(2)1254/16-17(01) • LC Paper No. CB(2)1288/16-17(01) • LC Paper No. CB(2)1326/16-17(01)
14.	Mr LAI Ka-wai	• LC Paper No. CB(2)1128/16-17(07)
15.	Ms LI Shui-yin	• LC Paper No. CB(2)1214/16-17(04)
16.	Ms CHI Yin-lan	• LC Paper No. CB(2)1128/16-17(04)
17.	Miss NG Hei-tung	• LC Paper No. CB(2)1128/16-17(10) • LC Paper No. CB(2)1214/16-17(03)
18.	Mr FONG Chi-wai	• LC Paper No. CB(2)1128/16-17(11)

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