K P Tsang, President, Hong Kong Alliance for Rare Diseases (HKARD)

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K P Tsang, president of the Hong Kong Alliance for Rare Diseases (HKARD), shares the challenges faced by patients with rare diseases and their caregivers in Hong Kong, the areas of improvement when it comes to rare disease policy, the advocacy work that HKARD is undertaking, and his insights on how patient associations can effectively organize themselves for greater impact.

Can you begin by introducing the Alliance for Rare Diseases and why there was a need for an organization like this in Hong Kong?

The Hong Kong Alliance for Rare Diseases (HKARD) was founded in late 2014 to unite patients of all rare diseases in Hong Kong. Individually, the number of patients of each rare disease is small, and it is not easy to form their own patient groups. When we formed this organization, our aim was to gather and amplify all the voices of rare disease patients and caretakers, and to make them heard to the public, the government, and legislators. This way Hong Kong society can understand what rare disease is and recognize the gaps that exist between patient needs and the current system. Together we seek improvement with all stakeholders.

There is a small number of specific rare disease associations and we work closely with all of them. HKARD's lies in our connections to government and policymakers, and also the pharmaceutical industry. On the other hand, the individual rare disease groups have close relations with patients and caretakers. This way we can collaborate together from different angles. The groups mainly

provide support and services to patients while we collect information and opinions and reflect them to the government representatives and media.

What activities does the Alliance arrange and organize in order to address the needs of the patients it represents?

We have met with different patient groups to exchange views and educate patients and their families about the healthcare system. For instance, many patients do not understand how they can get help from the system, so we hold meetings to inform them about the options that exist. We also want to know what their genuine needs are, and whether they are being met.

Most commonly, these would be in the areas of diagnosis, drug treatment, and coordinated care. As an example, we are advocating for the government establish a case managers' program to deal with rare diseases. Many patients have to navigate ten or even more different disciplines within the hospitals, which can be confusing. If the government could arrange this kind of program, case managers would be able to assist patients by assessing their needs, scheduling consultations, making referrals, and also arrange other care sessions like occupational therapy.

One of our proudest achievements has been bringing the issue of rare diseases into the media spotlight over the last few years. In the past, there was very little coverage on rare disease but now every week, we see some news stories on rare diseases in HK, from newspapers to magazines to television and electronic media. I think this is one of the most impressive impact we have had over the last few years.

What are the key challenges faced by rare disease patients in Hong Kong?

The first main issue is about diagnosis and examination. In Hong Kong, there is no clear definition of rare disease or any domestic rare disease programs. The Hospital Authority (in charge of overseeing the public healthcare system) has made statements saying the organization is available to all disease patients, rare or otherwise. However, they have no dedicated initiative or resources to address the issue of rare disease. In many cases, a diagnosis can take more than five years. In the process, patients are sometimes misdiagnosed several times.

In Hong Kong, the government has no rare disease resource planning initiatives in hospital or universities. There is a very small number of specialists of rare diseases. I must say, however, that

those that exist are passionate and helpful. Whenever we seek advice from them, they are always quick to give us detailed information. We are very grateful for their support.

Nevertheless, the government needs a comprehensive planning to address issues related to rare diseases. To give you an indication, there is no clinical geneticist post in the Hospital Authority – a very important position in terms of dealing with the treatment and diagnosis of rare disease. In total, there are fewer than five critical geneticists in all of Hong Kong! This is why we propose that the Hospital Authority should create this post and a special career path for top medical professionals who are interested in pursuing the field. In general, we need more concerted and targeted efforts like this.

How do you assess the government policies surrounding rare disease?

In terms of rare disease, the government is looking to reform two areas. First, they are planning on improving the co-payment mechanism for rare disease drugs. They have commissioned consultants to undertake the study of the current co-payment system and produce an interim report. The report was submitted to the Legislative Council in June 2018 and the final report should be published at the end of this year. Throughout this process, our Alliance has frequently discussed with the contracted consultants. The consultants had several focus groups with patients and their caretakers to collect their concerns and comments, which we helped to organize.

Based on the interim report submitted in June, HKARD has made formal suggestions to the government related to the key points they are considering for reform. In a potential new co-payment system, we see a need for three main changes, the first being the definition of family in the system. When patients apply for the drug subsidy, the family unit of the applicant includes parents, siblings, and children.

Here, we suggested minimizing the scale of a family unit. Our suggestion is that every Hong Kong citizen should be considered an independent family unit when they turn 21 years old. If an individual gets married and has children, these are the people that will then be considered their family in the system. Later, when those children turn 21 years old, they once again will become an independent family unit. In the past years, the family size issue has been very disruptive to patients. For instance, many families who want to apply for subsidies sometimes have had to divorce in order to receive adequate subsidies within the system.

The second point of change in the system deals with how to identify the assets used in the calculation of co-payments. Our suggestion is to use recurring income like salaries or rent earnings while exempting existing assets such as the patients' home. Additionally, the income being considered should be the net amount after deducting all taxes and other essential costs of living.

Finally, the third point addresses the ratio rate of how much patients are expected to pay after the calculation of their assets. The new system we have proposed will begin with a ten percent co-pay in the first year, progressively decreasing over ten years to zero.

Secondly, the government is working on the supply of drugs available to rare disease patients. HKARD has proposed new guidelines for the process of how new drugs, especially those for rare diseases, are listed on the Hospital Authority formulary. Hong Kong has no clear definition of rare diseases so bringing the most innovative treatments to the SAR is a challenge. Under the existing formulary listing process, extensive clinical data is required but this is very difficult for rare diseases, which by definition have smaller patient populations. We suggest that the Hospital Authority consider alternative methods for investigating rare disease drugs.

As an expert in patient advocacy, what are some best practices you can share with similar associations working towards the improvement of rare disease healthcare?

As an advocacy organization, the first step is to mobilize patients and caretakers to speak out. Only if they speak out will their real stories be heard.

Next, there must be collaboration with all stakeholders involved including government policymakers, healthcare professionals, academic institutions, and industry players. Most pharmaceutical companies have corporate social responsibility initiatives and therefore they can offer support in terms of funding, information, and education. On the government side, there is much room for improvement but we continue to strategically work together.

Another force that can be influential is the media. Having coverage by news outlets helps raise the public awareness of rare diseases.

The last thing to remember is the most important and fundamental: the patient must be the main priority of healthcare organizations.

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