James Chim â?? Chairman and Founder, HKSOM

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Professor James Chim, chairman and founder of the Hong Kong Society of Myeloma, shares the history and key objectives of the organization. He also elaborates on the recent milestones achieved regarding the treatment of the rare disease.

Can you begin by introducing the Hong Kong Society of Myeloma and what was the need for an organization such as this one?

The Hong Kong Society of Myeloma (HKSOM) was formed in January 2010. A few years prior to the establishment of the society, doctors witnessed tremendous advances in the treatment of the disease, and rise in myeloma cases in Hong Kong. Myeloma is not a common disease and only comprises around 350 new cases a year. Due to the aging population of Hong Kong, there has been a steadily increasing number of cases, and surprisingly, an emerging trend of occurrence in younger demographics as well.

Before the establishment of the society, we also found that the protocols of treatment for myeloma patients varied from hospital to hospital. Hong Kong does not have a national rare disease program, therefore, there is no national standard on how to treat diseases like myeloma. Moreover, haematologists are busy, and do not always have the time to review the vast amount of clinical trials to inform their treatment regimen. Once this discrepancy was realized, we decided to establish the society.

Our first priority was to share with our colleagues the most updated information on myeloma treatment and unify the treatment protocols of the disease across the health institutions of Hong Kong. This way we could solidify best practices and ensure that all patients are receiving the same level of treatment and best care possible.

Moving forward, HKSOM continues to educate health care providers by organizing conferences to share knowledge and discuss new ideas. Not only do we encourage dialogue among professionals in Hong Kong, we also invite overseas experts to participate in our meetings. We have hosted speakers from prestigious institutions such as Dana Farber Cancer Institute of the Harvard University, University of Torino, University of Salamanca, in addition to a 2-yearly joint HKSOM-Mayo Clinic annual scientific meeting since 2014. We also want to know how experts in the region are treating myeloma and have held conferences with Korea, Taiwan, Singapore, Thailand, and mainland China. These discussions give us an understanding of Hong Kongâ??s strengths, limitations, and areas for growth, from a global perspective.

How would you assess the current situation of myeloma treatment in Hong Kong?

There are many new drugs coming into the market that have been groundbreaking in regard to treatment response rate and patient remission. Myeloma used to be a miserable disease that caused a range of health complications including renal failure, anaemia, and bone pain and fractures. Treatment of the disease was difficult due to a poor response to conventional chemotherapy.

Therefore, the principal objective of myeloma therapy used to be comfort care â?? to help alleviate patient symptoms as much as possible. However, with the introduction of new drugs, we have modified these treatment goals. Thanks to cutting-edge technology, there is clear evidence of prolonged survival in addition to the palliation of symptoms with novel agents with much less side-effects. This is a major breakthrough.

An important milestone in myeloma treatment was the advancement of autologous stem cell transplantation. This bone marrow transplant is a relatively low-risk procedure which utilizes the patientâ??s own stem cells. In just a few years, alongside the introduction of new inhibitor drugs, these innovations have revolutionized myeloma treatment and prolonged patient survival. Furthermore, recent developments in immunotherapy in the form of monoclonal antibody and chimeric antigen receptor (CAR-T) T-cell therapy will be ground-breaking advances in the treatment of this miserable illness.

Due to the use of chemotherapy, along with the complications that arose from the illness and treatment methods, myeloma had been a disease that required hospital admission. However, the development of technology has made the treatment process very ambulatory. What used to be an in-patient process can now be easily manageable in the comfort of patientsâ?? homes. Currently, about 90 percent of myeloma patients never require hospitalization during treatment. We have almost 70 haematology inpatients in the Queen Mary Hospital and fewer than three of them have myeloma. This is a major advancement in the quality of life for patients, not to mention the improvement of treatment response rate, complete remission rate, and prolongation of survival.

What are the key initiatives of HKSOM that will help to further meet the needs of myeloma patients in Hong Kong?

Originally, the society was established to educate doctors, unify treatment protocol, and learn from each other and from overseas experts. However, the needs of patients are also very important to us.

Being diagnosed with such a life-impacting disease that most patients know almost nothing about is an enormous burden, stress and struggle. We wondered how we can take a step to further support patients outside of the hospital. Our solution was to help them create their own patient groups. We arranged an initial meeting for those who were interested, and patients were very receptive to the suggestion.

Since the first meeting in October 2015, we help organize two meetings a year. This first was even reported on by the International Myeloma Foundation (IMF) for their newsletter *Myeloma Today*, a quarterly journal covering the disease and related activities. In the meetings, we discuss the diseases and give patients the opportunity to ask any questions they may have. We have also invited speakers to come and see the patients such as clinical psychologists, orthopedic doctors, clinical pharmacists, dietitians, and physiotherapists. We even have a pastor come and speak with patients. We understand that patients have many different religious reviews, but it helps give patients a sense of comfort and psychological peace of mind, which help them cope with the disease.

We are very pleased to say that the patient group has officially registered as the Hong Kong Society of Care and Share since March 2018. The groupâ??s mission is to help each other understand the disease, treatment, and find mutual support. We hope this group can work together to create a platform where they can exchange experiences and begin to advocate for their health care need. We are currently working to connect the group with the IMF. We believe this will help to further educate and empower the patients here in Hong Kong.

Another initiative the society has launched is a bi-annual symposium partnered with Mayo Clinic from the United States. The first symposium was in 2014 which was attended by six speakers from the Mayo Clinic, including Dr. Robert Kyle, a renowned myeloma expert. Our colleagues in Hong Kong had the opportunity to present some of their most difficult cases for an additional expert opinion. So far, we have organized two of these joint meetings and the upcoming third will be November 2018.

The HKSOM hopes to give new doctors who are interested in the field of myeloma an opportunity for international development and create a culture of global knowledge transfer. Despite challenges of limited resources, we aim to establish Hong Kong as a premier leader in the treatment of the disease.

What advice can you share with other patient societies to help them better serve the patients they represent?

It is important to identify unmet patient needs beyond regular medication attention. To cater to their unmet needs, a patient group is essential. As the treating physician, one can help in the establishment of the patient group by identifying and engaging consenting patients. Even starting with a small group of patients from one hospital can be effective â?? it is like sowing a seed. From the first patient gathering, the momentum will develop and roll over to other healthcare institutions. It is important to learn how to efficiently gather a core group of patients, involve them in the process, and empower them to take control of the initiative.

In the end, patient groups belong to the patients themselves â?? our role is to just help them along and facilitate communication with other institutions and NGOs so that they may grow. Professional societies may offer patients the necessary resources and information to support them in running patient groups of their own, which in a way helps them feel more in control of their condition.

As there are a number of quality biotechnology companies in the Greater Bay Area that are proficient in generating CAR-T cells, a state-of-the-art treatment of myeloma, I believe the government of the HKSAR may help to liaise with the mainland authorities, such that myeloma patients in Hong Kong may participate in CAR-T cell clinical trials in China. If this is possible, myeloma patients in HK will benefit from the advanced biotechnology in mainland China â?? an example of optimal use of skills and resources in the Greater Bay Area.

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