

JOINT SYMPOSIUM 2 (JCA/JSCO/JSMO/RCJ) : RARE CANCER IN ASIA : CURRENT STATUS AND CONSTRUCTION OF MEDICAL NETWORK ON RARE CANCERS IN ASIA

JS2 – 6 Rare Cancers China Programs starting up

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This speech includes three parts: Introduction of Rare Cancer China Programs; National Policy on rare cancers in China; What can be done for improving the living condition of rare cancer patients.

First, Introduction of Rare Cancer China Programs. While I start to handle Rare Cancer China Programs, I work in lymphoma association of China as well. Our organization also supports and incubates other rare cancers and rare disease patients support group. In the past we accumulated some experience in serving for patients. Rare Cancer China Programs were affiliated to Chinese Organization for Rare Disorders. The vision of Rare Cancer China Programs is improving the living condition of rare cancers patients.

Second, National Policy on rare Cancers In these 3 years, government has gradually paid more attention to health care system. We have new bureau to control the affairs of health care, especially in the insurance system. We also delivered the first national rare disease list. Although we do not have national rare cancer list, some rare cancers were listed in the national rare disease list now. According to this, government also tilt policy to some rare cancers now. New drugs of rare cancers have priority to be approved by Center for Drug Evaluation and Research.

Third, what can be done for improving the living condition of rare cancers patients. The real-world surveys about some subtypes of Rare cancers have been ongoing from 2017. Next year, we plan to introduce and publish a book about HTA and amplify the voice of patients via it. And we also help patients find their suitable clinical trials and advocate for help new drugs for rare cancers be covered by national insurance list. In this September, we will launch the first Rare Cancers conference in China and continue to learn more from Asia Rare Cancers Alliance.