

PANEL DISCUSSION 5 : MEDICAL COOPERATION AND FOR RARE CANCERS

PD5 – 4 Rare Cancer Center - All Activities for Rare Cancer Patients! -

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Rare cancer is defined as disease which affects less than 6 patients per 100,000 people. Up to 200 types of cancers are categorized as rare cancers. Because the total population is small, decision with diagnosis and treatment are more difficult than other typical cancers. Problems underlying rare cancer treatment include lack of experience, information, education & training, patient support, clinical research, basic research, etc. Therefore, patients with rare cancer are suffering in situations.

National Cancer Center opened the Rare Cancer Center in June 2014 to reveal the circumstance of framework and improve the treatment of rare cancers. Even further, in April 2018, National Cancer Center was designated as the central cancer center for rare cancers which goal is to establish an environment where patients with rare cancer can receive appropriate treatment.

Rare Cancer Center publishes the latest information of medical care and research with rare cancers on its website and social media and also regularly holds "Rare Cancers-Meet the Experts" seminars. Seminars are conducted by experts of rare cancer directed to patients and their family members. Furthermore, to improve individual treatment support, we established "Rare Cancer Hotline", which is managed by full-time staff and nurses who connect rare cancer patients to appropriate medical facilities and departments. Over 20,000 people have received consultations using "Rare Cancer Hotline" in 5 years since its establishment. We now can analyze the difficult circumstances of patient with rare cancers, such as where to receive appropriate treatment and insufficient information. In this presentation, I would like to introduce patient support initiatives at our Rare Cancer Center and make a proposal of the needs to provide better medical care for patients with rare cancer.