Abstract (lay version) of project

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Desmoid Tumors for Big Data Linkage

Desmoid tumor is a rare soft tissue tumor can result in significant pain and loss of function. It is estimated that there are 2-4 new cases/1,000,000 per year or in the US about 900 new cases a year. Treatment options include wide surgical resection and/or radiotherapy, but not all tumors are amenable to resection and recurrence rates have been reported to be 30-38%. At present there is no FDA approved systemic treatment for desmoid tumors. One of the criteria used to determine whether a novel agent is approved for standard clinical use is the ability to demonstrate clinical benefit. In patients with malignant disease this is defined as an improvement in overall survival. Given its rarity and overall benign nature, definition of clinical benefit relies on characterizing the natural history of the disease. At present, little data exists on the prevalence, disease impact on quality of life (QOL), limitation of activity, evaluation of disease characteristics that identify a poorer prognosis, impact of various interventions on disease course and QOL, development of patient reported outcome measures, overall survival. Such parameters are essential to benchmark novel therapeutics that are developed. We propose to collaborate with Fu Jen University to use a record linkage approach with the Taiwan National Health Insurance Research Data Base (NHIRD) and other databases to identify clinical characteristics of desmoid and better define the natural history of this disease.