

Abstract (lay version) of project

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"An evidence-based consensus on the treatment of desmoids/aggressive fibromatosis."

There are very few reliable data on treatment recommendations evaluated in a prospective fashion. Thus much is based on the experience and expertise of single physicians. Particularly the access to medical (drug) therapy is very much dependent on regulatory aspects with no drug registered to treat desmoids. There is great variation across countries with cost aspects often overriding treatment efficacy. It is also not clear whether there is a 1st, 2nd 3rd line therapy or whether all drugs available are of equal efficacy. We therefore want to analyze by an independent institute published data to answer four questions:

- 1) To which extent should the different mutational status of desmoid tumors influence treatment decisions
- 2) Is a watchful waiting strategy really the key after diagnosis of a desmoid is made and when to switch from a watchful waiting to active therapy.
- 3) Which medical treatments can be classified as active in the disease and are there proven differences in therapeutic efficacy to be used to develop a hierarchy of treatment steps once the indication for drug therapy is made.
- 4) What is the role of pain control and physical therapy in the management of desmoids and how does this interfere with the results of surgery, radiation therapy or medical therapy.