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The Management of Desmoid Tumors: A joint global evidence-based consensus approach for adult and pediatric patients

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Background: There are very few randomized studies providing thorough data and evidence on treatment decisions in desmoids. In this context, the Desmoid Tumor Working Group thought it necessary to evaluate existing evidence from publications to draw more data-based conclusions.

Methods: With financial support from DTRF, sos-desmoid, and SPAEN we asked the IFOM, Institute of Research in Operative Medicine at the University of Witten-Herdecke, Germany to analyse scientifically the published data to answer four so-called pico 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.

After having received the results report, we brought together 45 experts from all sites of the atlantic and pacific ocean including a representative from EMA (European Medicines Agency, London, UK) which is an important component when it comes registration of drugs to treat the disease.

A task force team had provided a written basic document on the relevant aspects of desmoid diagnosis and treatment (except of radiation therapy). This document was discussed frankly and thoroughly by the experts in Milan, Italy on June 18th, 2018. After the meeting the task force will generate a consensus paper to be circulated between participating experts. It will be published in a publicly accessible scientific journal.

During the DTRF meeting the most important aspects from this consensus meeting will be presented.