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Successful Implementation of an International Desmoid Tumor Virtual Tumor Board: A Novel Platform for the Management of Rare Tumors

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Objective:

As is the case with rare tumors, established management paradigms for desmoid tumor (DT) are lacking which leads to individualized and inconsistent approaches to care. With the desire to meet the needs of patients with DT and physicians worldwide, members of the Desmoid Tumor Research Foundation (DTRF) Scientific and Medical Advisory Boards developed the idea for a virtual forum (tumor board) for discussion of complex DT cases.

Methods:

The virtual tumor board was formed in 2017. A core group of committed discipline-specific expert panelists from pediatric and medical oncology, radiology, general and orthopedic surgical oncology, pathology and radiation oncology were identified. The mission of this virtual tumor board includes four key tenants: multidiscipline, resourceful, inclusive, and collaborative. A web-based platform was selected with funding and operations provided by the DTRF. Initially, invitations were emailed to identified sarcoma providers requesting case and/or audience participation. Subsequent queries to the DTRF or identified DT experts have been re-directed to the tumor board organizers for a formal request to submit their case for presentation. Patients or family members are precluded from participation. Presentation guidelines are provided to each presenter in advance. Meetings occur quarterly with 3-4 cases presented at each session. All presentations are reviewed in advance to ensure HIPAA compliance. Beginning in August 2019, presenters have been asked to complete a referral form (Figure 1). These forms are then returned to the presenter following the virtual session with a summary of the medical tumor board recommendations.

Results:

To-date, 12 tumor boards have taken place including 42 patient presentations. A summary of case demographics is provided (Table 1). Feedback from presenters, patients, and family members has been overwhelmingly positive as they find this to be an invaluable service.

Although limited, available and evolving evidence-based consensus guidelines and education are being disseminated during these sessions which will foster a better understanding of the disease and facilitate incorporation of best practices for patients with DT. Since it is critical to understand the outcome of the advice provided and if the tumor board is accomplishing its stated mission, we request and are accumulating follow-up data on previously presented cases.

Conclusion:

Facing the challenge of limited clinical trial and research opportunities, rare tumors often lack well-established management strategies. Virtual tumor boards provide a unique and cost-effective platform to reach more people and provide expert advice in a more formal scientific forum. As far as we know, this project is the first of its kind and could serve as a model for other rare diseases.

This abstract has been submitted for publication.

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Figure 1: DTRF Virtual Tumor Board Referral Form Template

DTRF Virtual Tumor Board Meeting
Referral Form

Tumor Board Date		**Has Patient Been Previously Presented (If yes, provide date)?**	
Patient Gender		**Patient Age**	
Submitted by		**Date of Diagnosis**	
Institution and Location		**Date of Submission**	
Site of Primary Tumor			
Clinical Information (including pertinent imaging findings, genetic testing results)			
Clinical trial?			
Surgery		**Date(s)**	
Radiotherapy		**Date(s) and dose(s)**	
Hormonal treatment		**Date(s)**	
TKIs		**Date(s)**	
Chemotherapy		**Date(s) and # of cycles**	
Other Treatment		**Dates(s)**	
Local Tumor Board Decision (If applicable, please briefly state outcome of local tumor board discussion)			
Outcome of Virtual Tumor Board Discussion and Recommendations			
Follow-up from Presented Case (Date and Outcome)			

Table 1: Overview of DTRF Virtual Tumor Cases since Inception in 2017

Age	Sites of Disease	Associated Syndromes	Country
Range: 1-65 years 25 cases < 18 years 17 cases ≥ 18 years	Extremity (15) Abdominal Wall (8) Multifocal (7) Head and Neck (6) Intra-abdominal (3) Other (3)	Familial Adenomatous Polyposis (3) Gardner's (3)	United States (28; 15 states) England (4) India (3) Australia (1) Iran (1) Ireland (1) Italy (1) Philippines (1) Portugal (1) New Zealand (1)