Letter to the Editor

rare tumors

Rare Tumors
Volume 12: 1–3

DOI: 10.1177/2036361320984532
journals.sagepub.com/home/rtu
SAGE

Successful implementation of an international desmoid tumor virtual tumor board: A novel platform for the management of rare tumors

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To the Editor: Aggressive desmoid-type fibromatosis (desmoid tumor; DT) is a rare mesenchymal tumor affecting children and adults at an incidence of 5–6 cases per million per year.[1] In general, established management paradigms for rare tumors are often lacking which leads to individualized and inconsistent approaches to care. This creates great uncertainty and angst among providers, patients, and family members. While local institutional multi-disciplinary tumor boards have been created to achieve management consensus for just such scenarios, many practitioners, particularly those at non-academic/referral centers, lack this resource or the panel expertise for the rarest of tumors.

The Desmoid Tumor Research Foundation (DTRF) was founded in 2005 with the mission of facilitating and funding research toward a cure for DT and supporting patients with information (dtrf.org). The DTRF constantly receives inquiries from healthcare professionals, patients, and family members for advice on the management of DT. Similarly, as is the case for other rare tumors, known experts in the field of DT are inundated with email queries from colleagues seeking guidance. These messages often contain limited information; yet, the recipient typically feels a moral obligation to respond resulting in recommendations that may or may not be appropriate.

With the desire to meet the needs of patients with DT and physicians worldwide, the DTRF initially raised the idea with members of its Scientific and Medical Advisory Boards of creating a virtual forum for discussion of complex DT cases. The idea was then taken to the annual DTRF International Research Meeting in 2017 where the virtual tumor board was born. The mission of this virtual tumor board includes four key tenants: multidiscipline, resourceful, inclusive, and collaborative. 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. A web-based platform was selected with funding and operations provided by the DTRF.

Initially, informational invitations were emailed to sarcoma providers throughout the United States 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. Health Insurance Portability and Accountability Act compliance is followed with all personal health information removed from the presentations which are reviewed in advance. Meetings occur quarterly with the first session taking place in December 2017. Typically, 3–4 cases are presented at each session.

Within the first year, it became quickly apparent that we needed to expand to incorporate international participation. To facilitate this, the time of the tumor board was moved to 11:00 am Eastern Time to best accommodate the worldwide time zones acknowledging that no time would be ideal for all. Beginning in August 2019, presenters have been asked to complete a referral form (Figure 1). These forms are then

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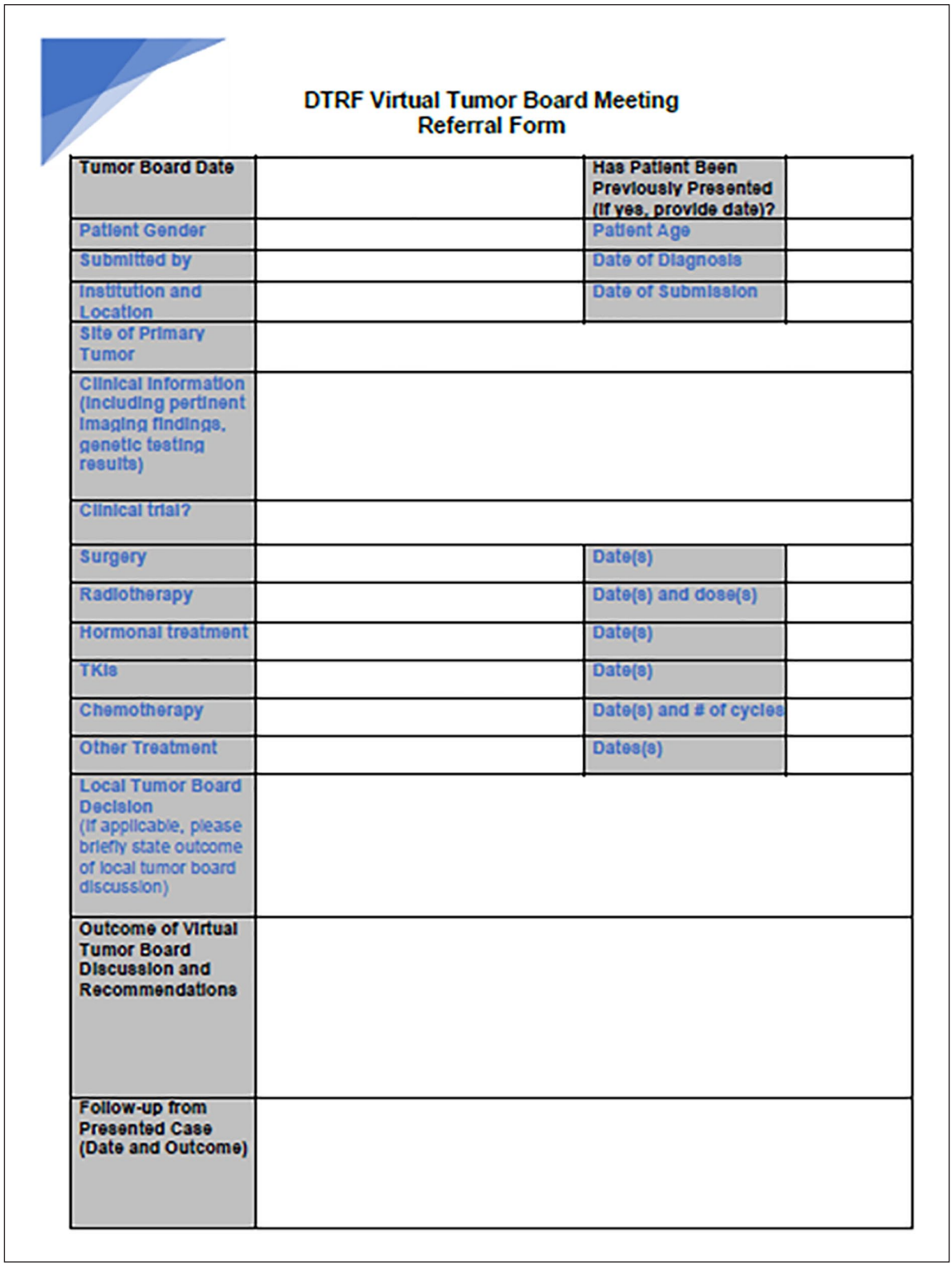

DTRF Virtual Tumor Board Meeting
Referral Form

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)			

Figure 1. DTRF virtual tumor board referral form template.

returned to the presenter following the virtual session with a summary of the medical tumor board recommendations. 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. At the time of this publication, 11 tumor boards have taken place including 39 patient presentations. A summary of case demographics is provided (Table 1).

Table 1. Overview of DTRF virtual tumor cases since inception in 2017.

Age	Sites of disease	Associated syndromes	Country
Range: 1–65 years	Extremity (12)	Familial Adenomatous	United States (27; 15 states)
	Abdominal wall (8)	Polyposis (3)	England (4)
	Multifocal (7)	Gardner's (3)	India (2)
22 cases <18 years	Head and neck (6)		Portugal (1)
			Australia (1)
	Intra-abdominal (3)		Iran (1)
			Ireland (1)
17 cases ⩾18 years	Other (3)		Italy (1)
			New Zealand (1)

Since undertaking this endeavor, a number of anticipated and unanticipated sequelae have been observed. As hoped, feedback from presenters, patients, and family members has been overwhelmingly positive as they find this to be an invaluable service and are greatly appreciative of our efforts. 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.[2] Unexpectedly, other rare tumor grassroots organizations have reached out for advice on how to duplicate similar endeavors which was the primary impetus to publish our experience.

In general, rare tumors often face the challenge of limited clinical trial and research opportunities which hinders the development of 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 for an individual tumor type and could serve as a model for other rare diseases.

Acknowledgements

We are indebted to Lynne Hernandez, director of special events and operations for the DTRF, for her countless efforts in coordinating all the DTRF-sponsored virtual tumor board sessions.

Authors contribution

ARW wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

Declaration of conflicting interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: ARW reports non-financial support from SpringWorks Therapeutics, outside the submitted work and he currently serves as Chair of the Desmoid Tumor Research Foundation Medical Advisory Board. The remaining authors declare that there is no conflict of interest.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Desmoid Tumor Research Foundation

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