

SARCOMA
COALITION

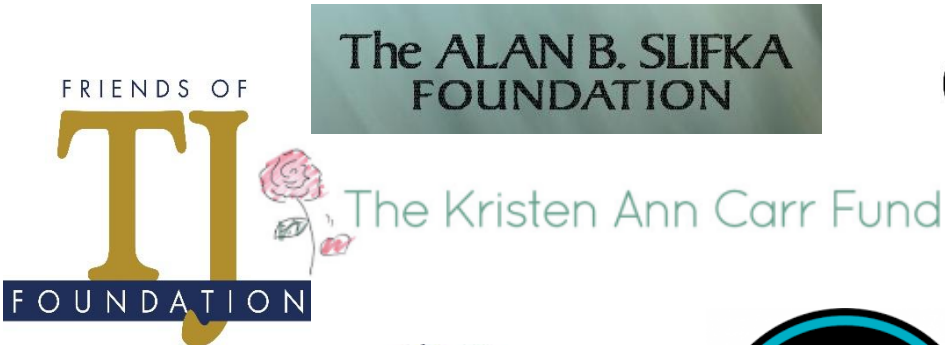
We are here for you.

- Formed in 2017
- Built upon collective interest to establish a platform to bring the multiple sarcoma advocacy groups together
- Overarching goals
 - Foster collaboration
 - Identify opportunities to leverage individual group strengths
 - Establish a collective voice to advocate for sarcoma patient
- We are 21 members strong!



SARCOMA COALITION

We are here for you.



THE DESMOID TUMOR
RESEARCH FOUNDATION



- **Core values**
 - Collaboration
 - Sense of urgency
 - Collective progress
 - Respect
- **“Group of Groups”**
 - Groups join the Sarcoma Coalition
 - Volunteers designated to represent their group participate in Sarcoma Coalition activities
 - Unaffiliated individuals interested in participating in the Sarcoma Coalition are encouraged to join one of the many sarcoma advocacy groups



- **Organizational structure**
 - **Member groups**
 - Select delegate/representative to vote and speak on behalf of the group
 - **Governance**
 - **Steering Committee**
 - Elected by the delegates
 - Oversee the activities of the group
- **Workgroups**
 - Initially established as an approach to engage organizations
 - Perhaps a premature approach
- **“Retooled” end of 2019**
 - Open forum meetings held every other month
 - Focused topic/presentation to stimulate discussion & group engagement
 - Sharing of ideas and activities for collaboration



Creating Positive Environment



**Participation
agreements**



**Conflict
Resolution**



Code of conduct

- **Website launched in 2018**
 - Target audience patients and families facing sarcoma diagnosis
 - Goal is to connect individuals to groups

www.sarcomacoalition.org
- **Newsletter launched in 2020**
 - Communicate with groups in between every other month webinar meetings
 - Share activities
- **Message Board**
 - Currently looking to find an electronic platform to share opportunities for collaboration



Sarcoma Coalition 2020 Goals

GATHER. LISTEN. EXECUTE.



Complete projects

Golf Ball
Message Board
Tool kit for raising awareness



Enhance connectedness of Sarcoma Coalition members

Virtual “happy hour”
Complete directory



Continue to identify potential new member organizations to join the Sarcoma Coalition

- **Leveraging strengths**
 - **Sharing group activities**
 - Educational programs
 - **“Alone we are rare, together we are strong”**
 - FDA
 - Legislative matter
 - **Educational materials**
- **Overcoming challenges**
 - Volunteer fatigue
 - Differences in approaches
 - Competing initiatives



Collaboration for Advocacy



SARC
**RESEARCH
ADVOCACY
COUNCIL**

SARCOMA
COALITION
We are here for you.

- SARC initiative to bring advocates and researchers together
- Built upon the NCI model of Research Advocacy Council
- Advocates from Sarcoma Coalition interested in become Research Advocate
- Training session December 2019
- Quarterly Council meetings
- Identified areas of interest/strength
 - Reviewing protocols &/or informed consents
 - Educating others about research
 - Participating in advisory boards
 - Disseminating research results
 - Raising awareness of available clinical trials



SARC
RESEARCH
ADVOCACY
COUNCIL



Questions & Discussion