



# Bone Sarcoma Alliance

*Where does this idea/initiative come from?*

It arises from:

- **SPAGN**- Sarcoma Patient Advocacy Global Network
- Patient/Parent group of the **FOSTER** Consortium



Sarcoma  
Patient Advocacy  
Global Network



# BONE SARCOMAS:

## Different diseases ... common concerns:



- Late symptoms recognition
- Late diagnosis/ misdiagnosis
- Disparities in access to MDTs/ pathways of care
- Lack of access to clinical trials
- Quality of life
- Late effects from treatment
- Lack of research
- Lack of support ( pain management/ rehabilitation/...)
- ....

# Bone sarcoma patient community



It is mainly composed by groups focused on a specific type of bone sarcoma.

# Bone Sarcoma Alliance



The **aim** of the bone sarcoma alliance is a simple one – **to bring together the patient groups/advocates from the different bone sarcoma communities** so that we can:

- Collaborate more effectively
- Learn from each other
- Amplify our voices
- Engage with clinicians and researchers on issues that are common to across all bone sarcomas

# How can BSA be defined?

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- It is an **informal partnership** initiative composed of
  - patient groups/ organizations,
  - patient/parent advocates and
  - patient networks.
- Its mode of operation will be '**working together as partners**' as part of the **SPAGN umbrella**



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# Bone Sarcoma Alliance



Current Steering Committee:

**Ornella Gonzato**  
**Pan Pantziarka**  
**Zoe Davison**

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