



Media relations policy

The Tuberous Sclerosis Association (TSA) is committed to an open policy on media relations and media engagement, as part of our focus on providing help for today and a cure for tomorrow for those affected by Tuberous Sclerosis Complex (TSC).

Any media queries relating to any aspect of the TSA follow the following Policy on Media Relations. This policy covers all forms of responses to the media, including “off the record” and anonymous statements.

First response to enquiries

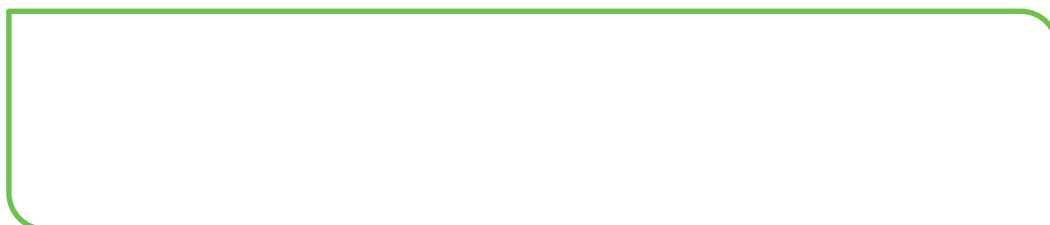
1. No TSA member of staff should respond to a media enquiry without consulting with the Senior Management Team (SMT) first, to ensure that our response is as helpful and comprehensive as possible
2. If a media enquiry is made through the telephone switchboard or TSA Support Line telephone number, the staff member should take details of the enquiry and contact details of the individual, and confirm with the individual that the enquiry will be discussed internally and a response shared as soon as we are able to do so

Developing a response and spokespeople

1. The TSA will try to respond to the media enquiry as quickly as is feasible, whilst also ensuring that all information is robust and up-to-date
2. All media enquiries are referred to SMT, for further discussion before a response is made. The Senior Management Team, other employees, Board Members or Specialist Advisors of the TSA as needed, will direct the process internally by which a response is made or position taken
3. To make media-charity engagement as straightforward as possible, a single TSA Spokesperson will usually be identified to engage with the media, following internal discussions
4. If follow-up questions regarding the enquiry are made and the TSA Spokesperson is not available, enquiries are to be referred to the charity’s Chief Executive, or a later date confirmed with the enquirer for the TSA Spokesperson to respond

The TSA’s stance on media engagement

1. The TSA appreciates the support that we receive from journalists and broadcasters, and the media’s helpfulness helping in raising awareness of TSC





2. The media and its associated services are viewed by the TSA as valuable sources, and engagement with the media in all of its forms is encouraged. The TSA will aim to also be a valuable resource to the media on TSC and other associated issues
3. The TSA commits to maintaining a proper tone of voice and manner when speaking with the media

Data protection and privacy

1. No private data or information will be shared with the media or any other third-parties when there is a data protection or General Data Protection Regulation (GDPR) concern
2. All enquiries regarding our privacy and confidentiality policies should be directed to:
 - [TSA privacy policy](#)
 - [TSA Support line confidentiality statement](#)

This policy can be reviewed, amended, updated, at any time.

Policy approved by Board: May 2021

Policy due for review: May 2022

The Tuberous Sclerosis Association
admin@tuberous-sclerosis.org

Main Switchboard: 0300 222 5737

Registered address: The TSA, Unit 56, 1 Emma Street, London, E2 9FP

Charity number: 1039549 (England & Wales), SC042780 (Scotland)