

The Tuberous Sclerosis Association (TSA) Notice of 2020 Annual General Meeting

Monday 26 October

Dear valued friend of the TSA

Invitation to the 2020 Annual General Meeting (AGM) and 2019 Impact Report

We are writing to invite you to the TSA's AGM on Thursday 26 November from 18.00-19.00. The AGM will take place virtually this year to keep everyone safe and well. Please visit tuberous-sclerosis.org/agm2020 to register your attendance so we can send you the link to the meeting.

2020 has been a challenging and difficult year for everyone, and it is a year that has shown how vital the TSA is to the TSC community. During the lockdown, many of our community have been shielding, and a key part of our work has been bringing people together virtually so that no-one feels alone with TSC. Although the TSA's income has been severely affected by the coronavirus pandemic, sadly leading to reductions in the size of our team, we are proud of the work that we continue to deliver to support individuals and families living with TSC.

At the 2020 AGM we will reflect on the TSA's 2019 achievements, which included:

- **Reaching more people:** during 2019 we held six community events across the UK. The number of people engaging with the TSA on social media and keeping connected with us is increasing. In 2019 there were hundreds of calls and emails to our advisers, covering a wide range of topics.
- **Driving more research:** while we no longer have large amounts of funding available to fund research on our own, the TSA jointly funded three new research projects plus a research study by working with partners who share an interest in TSC. These investments take our research portfolio to 12 projects with a value of over £1.2m.
- **Raising more money:** the TSA does not receive government funding and all of our activities are only possible through the generous support of individuals, corporate supporters and trusts and foundations. During 2019 we were delighted to have the support of internationally renowned actor Sir David Suchet CBE, who hosted a fundraising evening in aid of the TSA and prompted much media interest which raised awareness of TSC.

In addition, we delivered two substantial improvements for the TSC community. First, following a successful campaign, access to Everolimus for TSC-related refractory epilepsy was secured in England and we assisted patients seeking access in Wales and Northern Ireland. (We successfully secured access in Scotland during 2018.) Second, we supported the implementation of new UK clinical guidelines

The Tuberous Sclerosis Association
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on TSC, which are an evidence-based tool aiming to improve the consistency and quality of care across the NHS, with materials for the TSC community.

The AGM is a great opportunity to hear from the TSA and to make sure that we understand what is most important to you. As part of the pack sent with this letter, you will find:

- Notice of the TSA's 2020 Annual General meeting
- Our Impact Report, outlining our achievements in 2019
- Our Treasurer's Report, Strategic Report and Summarised Statement of Financial Activities and Balance Sheet for 2019 (you can find this information at the back of the Impact Report)
- A flyer for our ever-popular Christmas cards, with new designs for 2020.

Please read through these documents ahead of the AGM. This is your opportunity to raise any questions you have with the TSA Board. If you cannot attend the AGM but wish to raise a question, please write to AGM question, Chair, TSA, Unit 56, 1 Emma Street, London E2 9FP, email chair@tuberous-sclerosis.org or call us on 0300 222 5737.

Despite the challenges of 2020, we remain ambitious about what we can achieve for the TSC community. Our mission is unchanged: to provide help for today and a cure for tomorrow.

Yours sincerely,

Sanjay Sethi
Chair of Trustees

Martin Short
Deputy Chair of Trustees

Dr Chris Kingswood
President

PS. Please share the report with your friends and colleagues as we would like as many people to know about our vital work as possible.

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