

The Tuberous Sclerosis Association (TSA) Notice of 2021 Annual General Meeting

12 October

Dear valued friend of the TSA,

Invitation to the 2021 Annual General Meeting (AGM) and 2020 Impact Report

We are writing to invite you to the TSA's AGM on Thursday 18 November from 19.00-20.00. The AGM will take place virtually using Zoom again this year to keep everyone safe and well. Please visit tuberous-sclerosis.org/agm2021 to register your attendance so we can send you the link to the meeting.

At the 2021 AGM we will reflect on the TSA's 2020 achievements. In 2020 we urgently reviewed our business plan after the coronavirus pandemic caused extraordinary changes in the external environment. Trustees were worried about the impact of the pandemic on people living with TSC and their families, many of who were already isolated and living in difficult circumstances. We wanted to make sure that the TSA could meet their needs now and in the future. During 2020 we continued our focus on the TSA's strategic priorities, delivering them in innovative new ways to meet the challenge of the pandemic:

- **Reaching more people:** Through our new Support Line which launched in January 2020 we provided emotional support and tailored information about TSC and coronavirus by email and telephone. We organised monthly webinars and virtual get-togethers to bring people together and reassure people living with TSC and their families that they were not alone while shielding or self-isolating
- **Driving more research:** We delivered a virtual International TSC Research Symposium bringing together over 140 clinicians and researchers from across the globe. We were determined to strengthen links across the global scientific community and ensure that the pandemic did not disrupt progress with research that brings hope for the future to individuals and families living with TSC
- **Balancing the books:** We continued to take the difficult decisions needed to manage our finances with a view to balancing the books by 2022 or 2023. We carried on addressing the charity's structural deficit by significantly reducing both expenditure (from £1,000,461 in 2019 to £614,314 in 2020) and headcount (from 13 posts at the start of 2020 to nine posts by the end of 2020). These staff cuts were the second round of redundancies needed to make the charity the right size for the future

During 2021 we continue to deliver the TSA's 2019-2023 five-year strategy. Our priorities this year include: reaching more people by embedding our new Support Line and improving access for family carers and young people with TSC; hosting the virtual 2021 International TSC Research Conference which moved from 2020 to minimise the impact of the pandemic on delegate numbers and sponsorship income; and balancing the books while working smarter to improve the quality of our services.

admin@tuberous-sclerosis.org | 0300 222 5737
The TSA, c/o Nightingale House, 46-48 East Street, Epsom, Surrey KT17 1HQ
Charity number: 1039549 (England & Wales), SC042780 (Scotland)



We are closing our small office and becoming a wholly home-based organisation from 1 October 2021, as part of our ongoing determination to work efficiently and invest as much of our money in activities that benefit people living with TSC and their families as possible. Please update your address book with our new postal details below.

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 2021 Annual General meeting
- Our Impact Report, *TSA A Year in Review 2020*, outlining our achievements in 2020
- Our Treasurer's Report, Strategic Report and Summarised Statement of Financial Activities and Balance Sheet for 2020 (you can find this information at the back of the Impact Report)
- A flyer for our ever-popular Christmas cards, with new designs for 2021 including a card designed by our talented competition winner 10 year-old Jasmine whose brother Leo lives with TSC

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, The TSA, c/o Nightingale House, 46-48 East Street, Epsom, Surrey KT17 1HQ, email chair@tuberous-sclerosis.org or call us on 0300 222 5737.

Despite the challenges of the past two years, 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 keep an eye on your emails and on the TSA's social media channels as this Giving Tuesday (30 November 2021) the TSA is taking part in The Big Give Christmas Challenge 2021, and for just one week all donations will be **doubled!**

Not signed up to our monthly e-newsletters? Register today at tuberous-sclerosis.org/newsletters.

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