



# Tuberous Sclerosis Association

## Summary of TSA services

- To provide support for today and a cure for tomorrow for those with Tuberous Sclerosis and all who care for them. •

The Tuberous Sclerosis Association (TSA) was formed in 1977 by a group of parents, affected individuals and doctors interested in promoting greater understanding of the condition and providing mutual support for affected families. Our vision is to find a cure for Tuberous Sclerosis and enhance the lives of those affected.

### Information

The TSA produces a large selection of literature for people with TSC and their families, guidelines for doctors, and leaflets specially written for professionals such as teachers. The TSA website [www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org) includes medical and research information, forthcoming events and appeals and fundraising. The online discussion forum on the website can help people make connections and provides support.

### Support

The TSC Advisers can put families or individuals in touch with one another and offer advice on a range of issues associated with tuberous sclerosis, as well as recommending additional sources of help.

Our member magazine, Scan, is produced three times a year. It includes updates on research, treatment and management of TSC and also welcomes contributions from people living with TSC, their families and professionals.

### Education

TSC Awareness sessions and study days for professionals and parents and carers are provided in response to member and professional requests.

### Research

The TSA has contributed significant sums of money on genetic research in particular, which helped lead to discovery of the genes causing TSC and the development of DNA tests. A variety of other research continues to be funded by the TSA, including social, behavioural and clinical projects. The International TSC Research Conference, held every 3 years, provides an opportunity for doctors and scientists researching into all aspects of the disorder to share their newly acquired knowledge.

### Our Staff

All of our staff are part time workers and are based throughout the UK.

### TSC Advisers

Our TSC Advisers provide information, advice and support to families and individuals affected by TSC. They can be contacted by telephone, letter, and email and may be able to visit you at home.

Irene Craddy (The Midlands, Eastern England, Yorkshire and The Humber)

*TSA, PO Box 8001, Derby DE1 0YA, England.*

*Tel /Fax: 01283 711083*

*e-mail: [irene.craddy@tuberous-sclerosis.org](mailto:irene.craddy@tuberous-sclerosis.org)*

Fiona Clark (North-East England, North-West England and Wales)

*TSA, PO Box 8001, Derby DE1 0YA, England.*

Tel: 01625 427872

e-mail: [fiona.clark@tuberous-sclerosis.org](mailto:fiona.clark@tuberous-sclerosis.org)

Lynn Shields (Scotland)

PO Box 8728, Airdrie, ML6 WP Scotland

Tel: 01236 608257

e-mail: [lynn.shields@tuberous-sclerosis.org](mailto:lynn.shields@tuberous-sclerosis.org)

Maureen Tossi (Greater London, South East and South West England)

TSA, PO Box 8001, Derby DE1 0YA, England

Tel/Fax: 01865 865089

e-mail: [maureen.tossi@tuberous-sclerosis.org](mailto:maureen.tossi@tuberous-sclerosis.org)

Membership and Support Services Coordinator

Chris Johnson coordinates the TSA member events such as family days, Outlook event and the Annual conference. He also deals with all membership queries.

TSA, PO Box 8001, Derby, DE1 0YA, England.

Tel/Fax: 01332 290734

email: [development-support@tuberous-sclerosis.org](mailto:development-support@tuberous-sclerosis.org) or [chris.johnson@tuberous-sclerosis.org](mailto:chris.johnson@tuberous-sclerosis.org)

Appeals & Publicity

Anne Carter is your contact for press releases, information on fundraising and giving to the TSA:

Anne Carter, Head of Appeals & Publicity,

Tuberous Sclerosis Association, PO Box 7542, West Bridgford, Nottingham, NG2 9AY

Tel/Fax: +44 (0)115 923 4301

e-mail: [appeals@tuberous-sclerosis.org](mailto:appeals@tuberous-sclerosis.org)

Development and Support Services

Fiona McGlynn, Head of Development and Support Services, is your contact if you have any questions/feedback about the TSA support services:

Fiona McGlynn, Head of Development and Support Services

Tuberous Sclerosis Association, PO Box 8001, Derby DE1 0YA

Tel : 0121 4456970

e-mail: [fiona.mcglynn@tuberous-sclerosis.org](mailto:fiona.mcglynn@tuberous-sclerosis.org)

Research

Jane Cox (Head of Research) deals with applications for grants, organises the International Symposium, and is the source of information concerning the TSA's research activities:

Jane Cox MSc

Research Office, Sussex Kidney Unit, Royal Sussex County Hospital, Eastern Road, Brighton, BN2 5BE, England

Tel +44 (0)1273 696955 extension 4130

Fax +44 (0)1273 679788

e-mail: [research@tuberous-sclerosis.org](mailto:research@tuberous-sclerosis.org)

Jana Mbundi provides administrative support and assists the coordination of research awareness days and research events.

Jana Mbundi (Research Administrator)

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Further information on TSC and the work of the Tuberous Sclerosis Association can be obtained from our website at: [www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)

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While every effort is made to ensure that our publications are correct, please note that some information may change after the date of printing. Information in this leaflet is not intended to be a substitute for medical advice from your own doctors, who know your individual circumstances. We strongly recommend you talk to your doctor, and share the above information. The TSA cannot be held responsible for any actions taken as a result of using TSA information resources.